Doctoral School in Humanities and Social Sciences

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DEATH AND DYING MEDIATED BY MEDICINE, RITUALS, AND AESTHETICS

An Ethnographic Study on the Experiences of Palliative Patients in Finland

Maija Butters

DOCTORAL DISSERTATION

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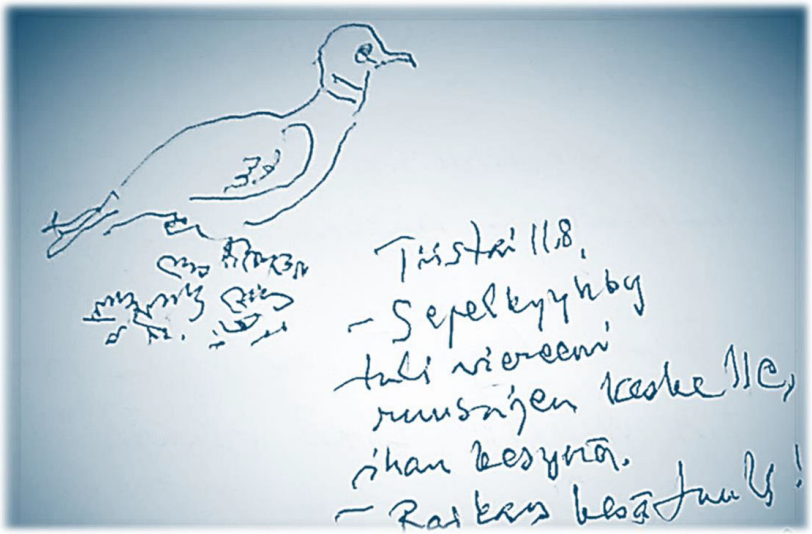
ABSTRACT

This dissertation is a phenomenologically oriented ethnographic study on the experiences of palliative and hospice patients in Finland. The overarching research question concerns how contemporary urban Finns, who have been diagnosed with a terminal illness, experience and negotiate their end of life, death, and dying. The study explores what kinds of language, imageries, and possible rituals exist in relation to dying, the variety of means that dying patients use to face their mortality, and how different environments and perspectives—medicine, rituals, and aesthetics—support patients in their negotiations vis-à-vis their existential situation.

The research material was gathered through ethnographic fieldwork comprising interviews and participant observation among terminally ill patients in 2014–2017. The research participants were recruited mostly from two locations, a hospice home and an oncology ward at a university hospital. The former became the primary research site. The analysis is based on data collected from 21 research participants, including materials that they shared (such as photos and artwork), and two blogs. A collection of ancillary materials (such as newspaper articles and reports from the Social and Health Ministry) helped to contextualize the subject.

The study explores and analyzes the ways in which patients received their terminal diagnosis, and how they were affected by different spaces and places toward the end of life. The main body of the work concentrates on the practices and activities around and by palliative patients from the perspective of ritual studies. The overall phenomenological orientation of the study highlights the embodied and embedded aspect of the research participants' lifeworld. This approach is complemented by critical mediated posthumanism as well as anthropological ritual theories. Together these locate the patients' illness and dying trajectories within the larger cultural and biomedical context. In addition, the study employs critical analysis of the dynamics of the care environments, using the Deleuzoguattarian conceptualization of striated and smooth.

The main findings of the study speak to embodied and mediated manners of experiencing death and dying, even as existential matters were expressed in relation to everyday life and corporeality. Rituals at the end of life were twofold: institutional medical rituals and personal ritualizations in the form of death avoidance rituals and death preparatory rituals. Of the various empowering and metaphysically meaningful frames that arose in the material, such as religion and spirituality, aesthetics and nature were the most accessible and efficient means for the research participants to process their approaching death and even find existential comfort as they proceeded toward their end of life.



A wood pigeon came next to me
into the middle of the roses,
all tamed.

Fresh summer breeze!

– Haiku by a patient written at the hospice home

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Acknowledgements

Many people have helped me to see this book through to its completion. In fact, I take this work as a result not only of my own research but also the many intellectual and collegial encounters that I have had during the whole Ph.D. journey. These encounters have broadened the horizon of my understanding and led me to new places in my thought processes.

First, I would like to thank my research participants, who trustingly opened their hearts and shared precious moments with me during their last months, weeks, and days of life. These meetings ended up in my dissertation as ethnographic data, but they also became an intense part of my reality, giving me lasting memories that affect the way I think about life and death today. I sincerely hope that in this study I have succeeded in conveying essential aspects of their perspectives and experiences. In addition, I wish to extend my thanks to the staff members in my fieldwork locations, who helped me in so many ways.

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During the years of sitting in different office rooms on the main corridor of the department, I enjoyed the supportive and sympathetic atmosphere of my colleagues in the Study of Religions at the University of Helsinki. I would like to express my deep gratitude to faculty members and fellow Ph.D. students, past and present, for stimulating discussions, moral support, and friendship. In particular, I wish to thank Professor Tuula Sakaranaho and those in the graduate seminar as well as the members of Terhi Utriainen's group of advisees; with them I had the opportunity to discuss my work in detail in a supportive environment. I also wish to convey my heartfelt thanks to Mitra Härkönen, Nina Maskulin, Ville Husgafvel, and Mari Pulkkinen, as well as Mulki Al-Sharmani, Alexandra Bergholm, Marja Ahola, and Johanna Konttori, all of whom were incredibly helpful during the most challenging moments of my research.

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In 2016–2017, I was fortunate to attend the so-called Trainer's Training for hospice educators, a program funded by the Common Responsibility Campaign's Good Death project, and coordinated by Terho Foundation with the help of Juha Hänninen, M.D. One of the highlights of the year was our visit to St. Christopher's Hospice in London, which proved to be informative in many ways. I thank the organizers of this training program, and especially all of the wonderful group members from whom I learned so much.

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These international encounters brought me further opportunities abroad. I was invited to spend a month as a visiting scholar in the Department of Anthropology at Utrecht University in the summer of 2018—thanks, Yvon, for facilitating this. Utrecht also became an important location to me because of Professor Rosi Braidotti's summer school sessions on posthuman philosophy, which I attended twice, in 2017 and in 2018. This opened up a new academic community and ways of thinking. I feel so fortunate to have met Evelien Geerts, Lucy Hill, Shiva Zarabadi, and Richard Lewis, who generously shared ideas and literature tips around my research. Special thanks go to Evelien, not only for her steady support and friendship but also for reading and commenting on my text, and conversing with me at great length about the finer philosophical details of existentialism.

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This work would not have been possible without the financial support that I received along the way. I thank the Church Research Institute and the Finnish Cultural Foundation for their research grants, and I consider myself so fortunate to have received a funded position in the Doctoral Programme in History and Cultural Heritage at the University of Helsinki in 2016–2018.

During the writing phase, I was able to engage in work retreats a few times at Tvärminne Zoological Station in Hanko. These stays were meaningful for my work—and especially for my psychological wellbeing. Writing in the midst of nature, running (literally) with lynxes, swimming in ice-cold water and enjoying a sauna with random fellow scholars—these were the best form of therapy I could have imagined. On this note, I would also thank my beloved Honbu Karate Club, which I joined in 2016. The practice of learning to hit the liver spot "just right" has taught me more about corporeality than any book ever could have. Arigatou gozaimasu to all my wonderful karateka friends!

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I dedicate this work to my mother, Raija Määttänen (1944–2014). I wish she could have shared this day with me.

On the Solar Eclipse of December 2020.
Maija Butters

PART I – SETTING

Prologue

It was a late summer afternoon and the sun was beaming through Kirsi's kitchen windows. We had met each other a few times at the day hospice, but had not had a chance for a proper conversation yet. Now she had invited me to her house and we were sitting by her kitchen table where she had brought various pictures and a pile of handwritten papers. I placed my recorder next to them. "You told me that you had something you wanted to share with me," I started (Kirsi/1). Kirsi seemed well prepared. "Oh, yes," she said, and began by telling me about an art project in which she had participated at the hospice home.[1] Kirsi had chosen to write about two art pieces: one was a painting featuring a warm Italian summer landscape with rolling yellow fields, while the other was a Finnish painting, which belonged to the hospice home's own art collection. "The second one was a more sombre one," Kirsi commented, and pulled out a picture from her papers and showed it to me. It featured a misty landscape with a small Finnish lake or perhaps a river.

Figure 1. The landscape painting by Finnish artist Maila Ponkkonen.1982. Photo: Maija Butters

[1] This research project aimed at analyzing the meaning of visual art for the hospice patients (Helin et al. 2018).

Kirsi looked at the picture on her table pensively:

> It is perhaps dawn or twilight, and those could be spruce trees on the right and some hardwoods on the left, but mainly I was [drawn] to the painting for its… The thing is that there is no heaviness here. The images mirror themselves onto the water and it is completely still and quiet. And that which reflects the future, whether it is about being alive or about the afterlife, if there is any such a thing (laughs), it *goes on* here… It is the same thing in the other painting. From both of them I found *continuity*. The water goes on. (Kirsi/1)

Kirsi proceeded to read the text she had written for the project, in which she depicted how she boarded a boat that started floating toward the shadowy mist—without knowing her destination but also not knowing fear (see Helin 2018; Helin et al. 2018). Kirsi's depiction led me to my next line of inquiry, which had to do with life and death as a landscape. Finally, I asked the question that intrigued me: "Have you ever assigned any color to death?" Kirsi fell silent for a moment, and then continued thoughtfully:

> Kirsi: I have encountered quite many deaths personally… and… a great anguish (*tuska*) relates to all of those deaths. What could be the color of that anguish? … It is not necessarily black or grey. Now I cannot say what would be the color of pain or suffering. On the other hand, it could be, for example, screaming red.
>
> I: Does this relate especially to pain, in a physical sense?
>
> Kirsi: Physical pain, precisely… and a sense of total hopelessness. And then, in the end, even when the person is unconscious, even then their eyelids are moving in such a way that one can imagine that they are still sensing pain. I don't know. I have only witnessed deaths that relate to pain. I have not seen other sorts of deaths. (silence)
>
> I: Mmm…
>
> Kirsi: And then, of course, when I think of my own death, I could imagine that it is that kind of… (gives a light laugh) grey… grey, that kind of light grey (*kevyen harmaa*). Because my wish is that… I have expressed my wish that when the time comes, I could be at the hospice home, and I have given them instructions and told my wishes about how I would like to be cared for.
>
> I: And how is that?
>
> Kirsi: Based on what I have experienced and heard of and seen during this illness, I absolutely wish for this… what was this again? It is not euthanasia but now I forget its name… it is… oh boy, what is it again?
>
> I: Do you mean sedation?
>
> Kirsi: Sedation! Yes, that's it. Because I assume that it is a soft death. One does not need to linger in pain until the very last moment. With this lung cancer, I know people who have been in pain, gasping for air until the end, and I want to avoid this. The doctor has promised me this—of course, depending on the various factors at that moment then. But this is what I have wished for.

I looked at the picture featuring the misty water surrounded by the hazy trees; it seemed to perfectly represent Kirsi's light grey, soft image of death.

This conversation with Kirsi—but one of many that I had with my twenty-one research participants—reflects well the mediated nature of the experiences of death and dying that I discovered during my ethnography. Here the mediatedness happens through contemplation on visual arts, but in addition to aesthetics, the experiences and perceptions of death and dying were mediated via various kinds of rituals and medicine. The role of medicine also becomes visible here in Kirsi's story, where, in the end, she refers to medical sedation as her preferred way to die. This discussion offers one example of how death and dying can be imagined and talked about in today's Finland. It is noteworthy how actively Kirsi participated in the creation of her own "deathscape" (Maddrell & Sidaway 2010), both by imagining her preferred end-of-life but also in practice by making her wishes known to the care staff. Not all of my research participants exercised their agency in the face of death as actively. The ability to affect one's situation and one's immediate environment in the end of life, as well as the way in which one is affected by the environment, comprises further key themes in this study.

In short, Kirsi's depiction offers a glimpse of an answer to my overarching research question of how contemporary Finns, who have been diagnosed with a terminal illness, experience and negotiate their end of life, death, and dying. The focus of this study is on the subjective embodied experiences of dying patients, as I sought to understand how people receive the news about terminal illness, how they orient themselves in the vicinity of death, and what kinds of tools they had in their use to handle their situation. Before going into detail regarding the topic and aims of the study, I will introduce some of the previous research and thus situate this work in the international field of death studies.

1. INTRODUCTION TO THE STUDY

1.1 Previous studies on death and dying

In Finland

Death studies is a multidisciplinary academic field that has been strongly growing in popularity for the last 15 years (Borgstrom & Ellis 2017). Within death studies, there are multiple approaches to the topic of death, dying, bereavement, and end-of-life care. Until recently, the most prevalent perspective in Finland has been that of nursing science, on which several doctoral dissertations around end-of-life care have been written in the last two decades.[2] A few Finnish studies concerning issues of end-of-life care have been written in the faculty of medicine.[3] In both of these fields, the studies have concentrated primarily on the care staff and relatives rather than the dying people themselves.

Another field that has been active in regard to studying death, dying, and bereavement in Finland is theology.[4] In the humanities, Finland has a rich tradition of death studies, starting as early as the turn of the 20th century (Waronen 1898) and continuing today in the disciplines of history, folklore, and folk beliefs surrounding death and dying (e.g., Pentikäinen 1968, 1990; Fingeroos 2004; Kemppainen 2006; Koski 2011). Outi Hakola's (2014) edited volume *Kuoleman kulttuurit Suomessa* ("Death Cultures in Finland") is a good example of contemporary thanatology, in which death and dying can be approached from such various angles as medicine, biology, media studies, philosophy, and history. The most recent additions to Finnish death studies are compilation books, the first one on the history of death in Finland, *Suomalaisen kuoleman historia* (Pajari et al. 2019), and the other on transcultural death (Saramo et al. 2019).

In my own field of the study of religion, in the last ten years contemporary death and dying have gained attention from students, resulting in several MA theses written on the topic.

[2] Terhikki Miettinen's dissertation (2001) focused on relatives' experiences of palliative care, Hilkka Sand (2003) studied hospice homes and their care culture, Varpu Lipponen (2006) studied the rapport between the primary (professional) caregiver and the dying patient, and in the latest study Mirja-Sisko Anttonen (2016) wrote about how dying patients encounter or dismiss the thought of dying, as well as what kinds of care can help patients come to terms with death.

[3] Hanna-Mari Hildén (2005) has written on physicians and nurses' views on the decision-making processes in end-of-life care, Marja-Liisa Laakkonen (2005) studied Advance Care Planning among the elderly, and Helena Karppinen (2019) explored older people's views on living wills. Reetta Piili defended her medical dissertation in 2019 on the changes of end-of-life decision-making among physicians and medical students in 1999–2015. In addition to these, Aili Huhtinen's (2005) dissertation on the discipline of adult pedagogy concentrated on death education among nurse practitioners.

[4] In her study about worldviews and religiosity among long-term, elderly hospital patients, Raili Gothóni (1987) touches on attitudes toward the end of life and death, and Gustav Molander (1999) wrote about elderly people's thoughts and attitudes toward death. The latest studies include Markku Siltala's (2019) analysis of experiences of the presence of deceased and so-called post-death contacts, Juha Itkonen's (2018) study on grief over stillborn babies, Matti-Pekka Virtaniemi's (2017) work on the existential processes of patients with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), and Suvi-Maria Saarelainen's (2017) study on meaning-making among young people with a cancer diagnosis.

Dissertations, however, remain few, and ethnographic studies are even scarcer.[5] Scholar of religion Terhi Utriainen's (1999) dissertation *Läsnä, riisuttu, puhdas* is one rare exception; her study profited from ethnography among the care staff at a hospice home and she wrote on the role of women as caregivers for the dying from an embodied perspective. Sociologist Anssi Peräkylä (1990) studied ethnographically relationships between staff members and dying patients in hospital surroundings, while sociologist Riikka Lämsä (2013) has examined the hospital ward and questions of anonymity from a material perspective in her dissertation *Potilaskertomus*. Lämsä's notions on how institutional practices construct the experiences of patienthood proved to be especially useful in my analysis of the affectual care environment.

My own focus on death and dying attends to dying persons, which here are regarded as "patients," since they are all in a professional medical care relationship. I am interested in how patients experience their situation of being terminally ill, how they feel about their trajectory of illness and their care, and how they think of death. This differentiates my study from many in the field of death studies. Especially in Finland, hospice and palliative care have previously been mostly studied from the perspective of care staff, on one hand, or from that of the bereaved, on the other. Although my understanding of subject is relational (i.e., subjectivity[6] is seen as generated from and realizing itself in dynamic embodied relations with the environment), I wanted to limit my scope here by concentrating on the patient. In my study, the surrounding people—whether they are medical personnel, family members, or other significant people in the patients' life—become visible only as part of the patients' experiential lifeworld.

The phenomenological notion of lifeworld (*Lebenswelt*, introduced originally by German philosopher Edmund Husserl in 1936) is used throughout the work as a way to accentuate the subjective experience[7] of the world and everyday life, which is at the center of my scholarly interest. The term "lifeworld," which is commonly used in phenomenological anthropology, creates the general theoretical frame for my study. It is akin to concepts such as lived body (*le corps vécu*), as contrasted with the body-object, originally introduced by French philosopher Maurice Merleau-Ponty in 1945. Later on, the phenomenological way of emphasizing lived experience became apparent in such concepts as lived religion (Orsi 1985) or lived eschatology (Venhorst 2012).

[5] Media anthropologist Anna Haverinen (2014) wrote her dissertation on death rituals and grief on the internet, whereas Mari Pulkkinen's (2016) dissertation in the study of religion explores the experiences of grief as described by people in their written narratives. Likewise in the field of the study of religion, Salome Tuomaala (2011) focused on women's agency in abortion and Leila Jylhänkangas (2013) wrote about euthanasia debates in Finland.

[6] The *Oxford Companion to Philosophy* defines subjectivity as "pertaining to the subject and his or her particular perspective, feelings, beliefs, and desires" (Solomon 2005). I prefer the more extensive definition by social scientists Ellis and Flaherty (1992: 1), according to whom subjectivity is "human lived experience and the physical, political, and historical context of that experience."

[7] I follow pragmatist John Dewey's approach to the concept of experience, according to which experiences are understood to occur when aspects of the world and the self come together in a manner that evokes emotions, ideas, and conscious intent (Dewey [1934] 2005: 36). More on the notion of experience can be found in Chapter 2.

International studies

Even internationally, ethnographic accounts on Western death and dying have been less common, especially within the realm of anthropology (Goodwin-Hawkins and Dawson 2018). In his recent article in *Annual Review of Anthropology*, anthropologist Matthew Engelke (2019) writes on contemporary trends within the anthropology of death, and even though he touches on some of the same themes which are central to my study (e.g., materiality and medicine), most of the actual research he discusses continues to be about the corpse, commemoration, and societal issues around the dead. The article does not mention any studies on actual dying processes, especially from the perspective of the dying themselves.

Some exceptions do exist, however. Of the international death studies literature, the most relevant works in regard to mine are two ethnographies on hospice from the UK (see also Kaufman 2005). [8] The first one, Jennifer L. Hockey's *Experiences of Death: An Anthropological Account* (1990), is a seminal anthropological study on hospice. Hockey investigates death and dying in two institutional settings—a residential care home for elderly people and a hospice—while also commenting briefly on a third setting, a bereavement support organization. My approach to the ethnographic material follows that of Hockey; she focuses on the cultural and social framing of human experience, and especially on the role of ritual and metaphor used in order to manage death in contemporary society (Hockey 1990: 81–89). Hockey did her ethnography in the 1980s, and both the UK and Finland have changed significantly since then in regard to elder care and palliative care. However, Hockey's theoretical insights continue to be valuable, especially the ones about the position of hospice itself as a ritual space and time, viewed especially in terms of liminality (Hockey 1990: 156–157). The major difference between our studies is that, unlike Hockey, I am particularly drawn to the patients' own endeavors to seek ways to handle their situation, whereas Hockey looks at hospice more from a systemic point of view, analyzing how various professional actors affect the construction of death. I continue Hockey's interpretation on hospice and other institutional care places as ritual locations, but add the individual ritual activities that patients practice.

Another study that has special relevance for mine is Julia Lawton's *The Dying Process: Patients' Experiences of Palliative Care* (2000). While doing extended ethnography at both a day hospice and a hospice ward, Lawton's theoretical questions revolved around the ideas of self, body, and personhood, and how they were constituted in contemporary Britain. Due to Lawton's personal and academic inexperience in relation to death (Lawton 2000: vi–viii), the corporeality and bodily aspects of dying shocked her once she started her ethnography. Subsequently, a large portion of her study reflects on and investigates the meaning of bodily

[8] The renowned North American medical anthropologist Sharon R. Kaufman wrote an influential account on hospital death in the United States: *...And a Time to Die: How American Hospitals Shape the End of Life* (Kaufman 2005). Many of Kaufman's notions (such as those relating to how death might be shaped not just by medicine but also by bureaucracy and technology) are relevant to my research, at least to a certain extent, but since her study focuses specifically on *hospital death* in the US context, it does not directly resonate with mine, which is about the patient's subjective experience of the end of life.

autonomy for personhood. One of Lawton's main conclusions was that, due to changes in admission policies (which reflected broader trends in care for terminally ill people), hospices have become "enclaves in which a particular type of bodily deterioration and decay is set apart from mainstream society" (Lawton 2000: 124). "In doing so," Lawton argues, "hospices and other similar institutions enable certain ideas about 'living', personhood and the physically bounded body to be symbolically enforced and maintained" (Lawton 2000: 124). This is an interesting argument, which my study comments on only indirectly. Lawton's remarks are noteworthy, because while healthcare policies are developed and realized nationally, they are framed by universal medical advancements and also by international recommendations in regard to palliative care, such as those presented by the WHO (2016). Furthermore, due to similar demographic shifts and advances in various diseases, as well as economic challenges, healthcare practices and policies exhibit global trends (Yeganeh 2019), and palliative care and care for the dying are no exception (Etkind et al. 2017; Kaasa et al. 2018: e589).

Hockey's and Lawton's works have inspired successive ethnographies, for instance, in regard to dying in Germany (Eschenbruch 2007; Menzfeld 2017). Lawton's embodied perspective and her concept of an "unbounded body"[9] (Lawton 1998, 2000) have been well appreciated and developed further, both in regard to dying patients (e.g., Probst et al. 2013; Håkanson and Öhlén 2014) and in regard to health and illness in general (e.g., Draper 2003; Howarth 2013). The issues of the care place and place of dying have also gained attention from several ethnographers (Morris & Thomas [2007] 2016; Broom and Cavenagh 2011). My study can be seen as a successor in this line, but bringing forth a new perspective from a country which is Western by its economic and political profile yet unique in terms of its historic and cultural position between the East and the West (see Butters 2017). This study contributes and brings variety to the contemporary academic discussion on death and dying in Western cultures, since until now the majority of studies have been produced either in Anglo-American countries or in continental European countries like the Netherlands.

A significant majority of these ethnographies (including those of Hockey and Lawton) are about the experiences of palliative care rather than the experiences of the end of life or dying *per se* (e.g., McNamara 2004; Moore et al. 2013). Sociologist and renowned death scholar Allan Kellehear (2014) has offered an exception by writing about the inner experiences of dying people and concentrating on non-clinical perspectives on the experience of dying. Kellehear (2016) has also criticized contemporary death studies for its distorted interest in the medical perspective of the dying, in which the focus is on the various kinds of medical sites. While I agree with his remark, it could be argued that medicine in general, and medical environments in particular, form an undeniable part of most people's everyday reality—particularly those who are seriously ill. Hence, the fact that much of the scholarly work has been concentrating

[9] With the term "unbounded body," Lawton wanted to draw attention to the "literal erosion of the patient's physical boundaries" (Lawton 2000: 128).

on the medical aspects of dying people's lifeworld reflects the actual lived reality. While in this ethnography I have recruited most of my research participants from medical sites, the actual study focuses on the variety of experiences that my research participants had. Furthermore, as I look into the experiential aspects of the end of life, such as those related to body and place, I analyze them not merely in regard to palliative care but as facets of the end of life and dying in itself. This is possible due to the phenomenological perspective on dying, which emphasizes the embodied relationality presented in my work.

In sociological studies, the concept of relationality is used in regard to interpersonal social relations (e.g., Broom and Kirby 2013; Ellis 2013; Broom 2015; Håkanson and Öhlén 2016). I use "relationality" in order to refer not only to interpersonal relationships but to various kinds of physical, psychological, and spiritual relations one can have with animate and inanimate surroundings. Accordingly, this general approach to the research topic situates my study in the field of phenomenological anthropology (Desjarlais & Throop 2011) or cultural phenomenology (Csordas 1994, 1996, 2011).[10] The phenomenological approach to the end of life and dying highlights the embodied, sensorial, and intersubjective nature of the subjective experience without failing to consider "the ways in which political, social, economic, and discursive formations intersect with the operations and felt immediacies of bodies" (Desjarlais & Throop 2011: 90). In this study, the latter aspects are included by applying ritual theories to the context.

British anthropologist Andrew Irving offers a phenomenological perspective on contemporary dying and living with a life-threatening disease in his latest book, *The Art of Life and Death* (2017). In this ethnographic study, which Irving conducted off and on during a period of over twenty years among HIV/AIDS patients in New York, he writes about the variety of lived experiences, imaginative lifeworlds, and aesthetic expressions related to dying. Irving focuses on the question of time, namely, how people with an HIV/AIDS diagnosis experience time in a frame of mortality and finitude in an era of rapid social, moral, and political change (Irving 2017: 12). Since "from a phenomenological perspective, time begins and ends with the lived body," his book is also essentially about the body (Irving 2017: 12). Irving reminds us that our bodies are always in movement; they are dynamic and ever varied, not only among persons, but also during the individual's life course, in health and in sickness. Irving seeks to study such variability in order to better understand "how the body creates the conditions for multiple modes of experience and expression" (Irving 2017: 19–20). Instead of theorizing his cases extensively, Irving converses with philosophy and the aesthetic material he has acquired from the field. In this way, the book attempts to "engage with recent debates in visual, sensory, and medical anthropology concerning phenomenological experiences and ways of knowing not

[10] Whereas phenomenology has been interpreted and defined in various ways throughout its history, one applicable way to define it comes from anthropologists Kalpana Ram and Christopher Houston, who explain that "phenomenology is an investigation of how humans perceive, experience, and comprehend the sociable, materially assembled world that they inherit at infancy and in which they dwell" (Ram & Houston 2015: 1).

just through theory, […] but […] through development of new ethnographic practices that aim to open up areas of research concerning the radical shifts in inner expression and aesthetic perception that have hitherto been overlooked in anthropology" (Irving 2017: 26). Although my way of doing ethnography, including my way of analyzing and manner of writing, differs from Irving's style, I find that we share the same key interests and ways of approaching the material. In particular, our works share attention toward embodied experience, situated perception, and aesthetics in the sphere of mortality and finitude.

In summary, most of the ethnographic research on death and dying has to do with either the care staff and their practices and perspectives, on one hand, or the experiences of the bereaved, on the other (e.g., Wright 2012; Lerer 2015). The dying themselves have been far less studied, especially ethnographically (Rier 2000; Lawton 2001). Furthermore, when the dying have been studied, the focus has often been on their experiences of care rather than on the experiences of the actual process of dying. By integrating both, my research fills a gap.

1.2 Research questions and the setting

Research questions

I started this study with an interest to learn about the experiences, needs, and wishes of hospice and palliative patients (see Appendix 1: Research Information). The actual research questions, however, were formulated in a processual way in relation to the fieldwork and thus became refined over the course of the study. The overarching research question concerns *how contemporary urban Finns, who have been diagnosed with a terminal illness, experience and negotiate their end of life, death, and dying.* I was interested in learning how terminally ill people orient themselves and how they craft their subjective lifeworld in the vicinity of death. The research question was approached ethnographically by studying 21 research participants, who were mostly recruited from a hospice home in 2014–2017. During the course of the fieldwork, my understanding of the research topic became more nuanced. I realized that while I was specifically interested in the experiences of the patients, in order to fully fathom those I had to also comprehend the environments in which they were engendered. In this way, over the course of the fieldwork, the main research question became more granular, comprising more specific sub-questions, whose findings contributed to the primary area of inquiry.

The first sub-question relates to the way in which the research participants convey their experiences; how they talk (or do not talk) about the end of life—or the afterlife, for that matter; what kinds of language they use; and what kinds of imageries they have in relation to death and dying. The second sub-question has to do with the environment and how the research patients are affected by various places and spaces, whether actual or virtual, especially in regard to augmenting or diminishing their agency at the end of life. The third sub-question inquires about the types of activities hospice and palliative patients engage in, and especially what kinds of rituals exist in relation to death and dying in Finland today.

The answers to these sub-questions help to build an understanding of the subjective experience of the end of life. Answers to the first sub-question, concentrating on what and how is communicated, speak to the various attitudes and ways of approaching the end of life, as well as fears and hopes related to death and dying. Answers to the second sub-question illuminate the way in which various factors, such as the environment, affect and construct the experience of dying and how different environments support patients in their negotiations in regard to their existential situation. Answers to the third sub-question speak to the various activities and rituals in which the patients were engaged, either actively or passively; furthermore, they shed light on what kinds of (practical) means dying patients have at their disposal for handling the issue of mortality.

The common element in all of these sub-questions is that they add to the understanding of dying as a strongly relational and mediated experience. It is worth noting here that the kind of previous experiences the patients had had during their whole illness trajectory, up to the moment I met them, greatly affected the way they experienced their situation at the moment of the research. In other words, the research participants' previous experiences (for instance, with medical encounters) impacted the way in which they interpreted their contemporary situation. For this reason, I found it important to include in the analysis the research participants' accounts of past moments of care and medical places.

In this way, the study describes how there are various ways to receive a terminal prognosis and live with it; it explores and analyzes the experiences related to the different spaces and places in which patients found themselves after their diagnosis, and how these places affected the patients' experiences of their end of life. In addition to questions relating to spatiality, the main body of the work concentrates on the practices and activities around and by palliative patients from the perspective of ritual studies. In brief, this study aims to illuminate the various kinds of experiences that terminally ill patients have, and to analyze the different kinds of rituals and ritualizations that patients engage in along their illness trajectories in proximity to death.

While the dissertation draws from phenomenological anthropology, it also belongs to the field of the study of religion. Within that discipline, the work is situated in the frame of lived religion (McGuire 2008; Orsi 2010), which emphasizes the everyday aspects, practices, and experiences of religiosity and spirituality. The concept of religion is much debated among scholars and there exists a variety of approaches to religion (see Woodhead 2011; Närvä 2020). From the perspective of existential crises related to the purpose of life and mortality, religion can be seen as one possible cultural system to help people navigate and orient themselves through difficult times.[11] Per the differences of religion and spirituality, I follow here the formulation by scholars of religion Paul Heelas and Linda Woodhead, which states that religion

[11] Most of my research participants seemed to understand the word 'religion' either as a direct reference to the Lutheran Church or as "a personal set or institutionalized system of religious attitudes, beliefs, and practices," thus following a traditional dictionary definition (https://www.merriam-webster.com/dictionary/religion).

"involves subordinating subjective-life to the 'higher' authority of transcendent meaning, goodness and truth, while [spirituality] invokes the sacred in the cultivation of unique subjective-life" (Heelas & Woodhead 2005: 5).[12] Approached in this manner, spirituality is linked with subjective and often this-worldly goals of life, whereas religion involves a transcendent element which inspires one to seek meanings beyond this world (Heelas & Woodhead 2005: 6). As systems of orientation, they thus consist of somewhat differing values and may lead to different goals.

In my initial research proposal, I asked if the Lutheran worldview and language hold a place in people's minds when they encounter a crisis such as terminal diagnosis. This question was in the background throughout the research process, but its role somewhat diminished during my ethnography. This was due to the reality I encountered with the patients, whose everyday life was typically colored by rather physical and concrete concerns, such as the ability to move, eat, and breathe, and consequently by the emotions related to these issues. To be sure, explicit existential and metaphysical questions surfaced—about the meaning of suffering, for instance—and I tackle these as well as other worldview-related aspects along the way. However, more space than I initially anticipated is given to analyses of the everyday relations that patients had, be they with humans (such as loved ones or care staff), animals (including pets), or technical aids (such as the intrathecal drug delivery device, commonly referred to as a "pain pump"; Finnish: *kipupumppu*) (see also Ellis 2013, 2018; Borgstrom et al. 2019).[13]

Furthermore, I will argue that everyday life, just as it is, has an existential value in itself and, furthermore, that value only increases as everyday life becomes more challenged and complex. In other words, it is not necessary to "talk religion" or "talk philosophy" when touching upon existentially and metaphysically meaningful issues but rather the opposite; existential matters are often encountered, discussed, and dealt with in terms of everyday, even banal, reality. One aim of this study is to give space to description and analysis of these kinds of encounters, in order to shed light on the vernacular that is pregnant with metaphysical significance. Approaching existential matters from an embodied quotidian perspective is common among scholars of lived religion, many of whom draw from phenomenological philosophy (see Knibbe & Kuparinen 2020). Similarly, the general theoretical frame of this study, that is, the phenomenological anthropology inspired by posthuman thinking, supports this manner of reading reality (Merleau-Ponty [1945] 2005; Csordas 1997, 2011; Braidotti 2006, 2011, 2013; Sharon 2014).

While the phenomenological approach is useful when the analysis of the research concerns the participants' perceptions and experiences, including those related to the environment, the

[12] It is important to note that this way of approaching the difference between religion and spirituality does not coincide with the way in which much of the Christian literature writes about spirituality (see Heelas & Woodhead 2005: 5).

[13] A drug infusion pump is a method of dispensing medication directly into the patient's circulatory system, and it is controlled by the patient themselves.

research profits from ritual theories (Bell [1992] 2009, [1998] 2009; Asad 1993; Schilbrack 2004) when analyzing the activities in which the research participants were involved. Furthermore, in order to grasp the meaning of both subjectifying as well as objectifying experiences in the field, the study draws on different aspects of ritual theories: those that emphasize the agency of the research participants as well as those which highlight more the structuring and disciplining aspect of the rituals. Overall, the phenomenological emphasis means that the analysis highlights the embodied[14] and embedded[15] experiences of the research participants. In other words, this study offers an understanding of terminal illness that is built from the lived experience of the patient.

As qualitative research, this study is not intended to be statistically representative, nor can claims be made about the extent to which the conclusions may be applied in general to the population. Rather, this study is illustrative by its nature; it offers insights into what potentially comprises a contemporary death in Finland.

Parameters of the study in brief

The research material for the study was gathered during ethnographic fieldwork among terminally ill patients in 2014–2017. The ethnographic research methods comprised ethnographic interviews and participant observation. I had two research sites, for which I had been granted research permissions since receiving approval for the research by the medical ethical board of a university hospital.[16] One of the research sites was an oncology ward at a university hospital, and the other one was a hospice home. In the end, and for reasons I will explain in due course, the hospice home, and especially its day hospice unit,[17] became the primary research site where I spent a great deal of time over the next three years. It should be underlined, however, that this is not a study about any particular care place or medical site, nor is it about palliative or hospice care *per se*, but rather, as already stated, it is about people's experiences of their life with a terminal prognosis—and their eventual death.

For the first six months of the ethnography, I attended the day hospice weekly; after that I had a five-week research period at the hospice ward (divided into two parts) and a four-week period at the oncology ward. From there on, I continued visiting the same day hospice group with which I had already worked for months and occasionally the hospice home to meet with a

[14] Here "embodied" refers to the phenomenological concept of "embodiment," which goes back to philosopher Merleau-Ponty's ([1945] 2005) understanding of the irreducible fusion of mind and body. For Merleau-Ponty, the body was not simply "a vessel controlled by the mind"; instead, he thought that "the mind realizes itself through the body" (Williams & Annandale 2014). Therefore, the body actually shapes our perceptions of, and our way of being in, the world; this is known as "embodiment." The phenomenon of embodiment will be discussed throughout the book.

[15] Here "embeddedness" refers here to the contextualized and relational understanding of a human experience. People and their experiences are viewed as dependent of and situated in a certain geographic and societal environment at a certain time with certain economic and cultural influences.

[16] The Coordinating Ethics Committee of the HUS Hospital District granted me research permission in regard to the university hospital and the hospice home until 1/1/2017 (record number 242/13/03/00/2013).

[17] Day hospice is an outpatient facility where patients are sent by their doctor's referral. Patients receive medical consultation at the day hospice, and there is a peer group and important psycho-social support available.

research participant. After 18 months of fieldwork, my visits grew more seldom but I continued to visit the hospice home once or twice a month for about three years altogether. I also kept in contact with my existing research participants by phone and occasionally visited them at their homes. Due to the natural process of the research participants passing away, the fieldwork ended after I ceased to take on new participants. By the end of my ethnography, the research included 21 actual participants, of whom fourteen were women and seven were men.

The research material comprises 170 pages of transcribed interview material, as well as four field diaries with about 350 pages of text. In addition to this, my research participants shared some aesthetic materials with me, such as photos, artwork, poems, and other texts that had been meaningful for them. Two of my research participants also wrote blogs, which I used in my analysis. In addition to the actual research material, I collected ancillary material, which includes newspaper articles on hospice and palliative care in Finland, reports from the Social and Health Ministry, and so forth. I also attended seminars and conferences on death and dying and hospice care. This ancillary material proved important, since it helped me to contextualize some of the issues that arose in my research.

In addition to these, I gained some perspectives on the topic of death and dying through personal experience. During my intense fieldwork period, my mother was suddenly diagnosed with terminal lung cancer. She died only four months after her diagnosis. She was never assigned to palliative care, and my experience with her provided me with additional insight into how one could experience their end of life without palliative care.

Terminology and the reference techniques

Terminology

In this work, the term "terminally ill" is used for referring to a patient who has a terminal diagnosis or terminal prognosis. According to the literary review done by Dr. David Hui, "terminal diagnosis" and "terminal prognosis" do not have a definitive meaning in the medical and nursing sciences; most commonly, the terms refer to a diagnostic situation in which patient is expected to live less than 12 months (Hui et al. 2014). A "terminal condition" can be defined as one in which "to a reasonable degree of certainty, there can be no restoration of health, and which, absent artificial life-prolonging procedures, will inevitably lead to natural death" (McCartney & Trau 1990, cited in Hui 2014). The common advice for physicians about the correct time to start planning end-of-life care is when "the attending physician would not be surprised if the patient dies within the next six to twelve months" (Current Care Guidelines 2019). However, estimating life expectancy is notoriously difficult, and therefore it is possible for a patient to die earlier than predicted or to outlive their life expectancy by months, and at times even by years. However, since this research concentrates on the patients' experiences upon learning about their terminal condition, the accuracy of their medical prognosis is of interest only from the patient's experiential perspective, that is, how it may have affected the patient's experiences of their end of life.

Since the term "terminal patient" has become obsolete (Saarto 2020, personal communication) I have used the term "palliative patient" when referring to my research participants. At times I also use the term "hospice patient," especially when I talk about someone in hospice care. Occasionally, I also use the term "dying patient" which in medical language, refers to a patient whose life expectancy is only some days or weeks, a couple of months at most (Saarto 2020, personal communication). All of these definitions have the term "patient" within them. It is a conscious choice. All of my research participants were technically speaking in a patient care relationship with some medical institution and this is also how I recruited most of them. Even more importantly, *patienthood* was a meaningful facet of my research participants' identity and their end-of-life experiences. The term was not therefore only an *etic* categorization given to them by medical institutions but it was also their own *emic* term, which they used when referring to themselves.[18] Whether they identified themselves as *dying* patients is a different matter, which I will address in my analysis. Overall, however, the study is about the research participants' experiences as palliative, hospice, or dying patients.

Other key terms used in this work are palliative care (*palliatiivinen hoito*), end-of-life care (EoLC) (*elämän loppuvaiheen hoito*, *saattohoito*), and hospice care (*saattohoito*). These three concepts are intertwined yet different. Historically, the roots of palliative care lie within the hospice movement. The principles of hospice philosophy in turn were developed, among others, by Cicely Saunders at Saint Christopher's Hospice in London in the 1960s, whence the hospice ideology quickly spread around Anglo-Saxon countries. In 1973, Canadian doctor Balfour Mount founded a new unit for terminally ill patients in Montréal. Initially, he thought of naming the unit a "hospice," but since in French the word was already used to describe a nursing home for the poor and the destitute, he decided to call it a "palliative care ward" (Pastrana et al. 2008). Since the 1970s, the meaning of palliative care has become broader, and in the course of the past decades it has been defined in multiple ways. Even today, there exists some debate about the definition (see Clark 2019). I rely on the definition given by the World Health Organization:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO 2019)

Palliative care encompasses more than end-of-life care, however, and it actually does not have any set duration. It is aimed at individuals who have a serious illness in which a cure or complete reversal is no longer possible, and it involves controlling symptoms that have either an insidious onset and progression or a rapid onset and progression (Krau 2016). In practice, palliative care

> provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as

[18] In the social sciences, *emic* refers to the subjective perspective and concepts of the researched, while *etic* refers to the perspective and conceptualization of the researcher or, here, those of institutions.

> possible until death; offers a support system to help the family cope during the patients' illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. (WHO 2019)

The term *end-of-life care* describes the kind of palliative care which is offered toward the end of life for those patients with a terminal prognosis and life expectancy of less than twelve (or six) months. In the international literature, *hospice care* has a very similar definition as end-of-life care. However, contrasted to the definition in English, hospice care in Finland refers to the *care of imminently dying patients* with a life expectancy of days or weeks (Current care Guidelines 2019) rather than months (Hui et al. 2012). It is generally seen as the last phase of palliative care, in which the alleviation of physical, social, psychological, and existential pain is the most pronounced feature (Saarto 2017: 7).

In sum, the terminology is varied and also dynamic. In a literary review article written by Hui et al. (2012), there are several possible reasons for the lack of standardized terminology in palliative care. Since these aspects seem international enough to affect also the Finnish palliative care, I quote him here:

> First, unlike many established disciplines, palliative care is still trying to find its own identity within the health care system. Second, the multidisciplinary nature of palliative care means that there is a plethora of viewpoints and perspectives from different professional organizations. Third, some of the terms such as "palliative care" can be interpreted as a philosophy, concept, approach, program, service, specialty, or knowledge domain. The pleomorphic nature invites diverse interpretations. Fourth, the sensitive nature of palliative care has led to a creative list of euphemisms over time. […] Fifth, significant regional variations in the structures and processes of palliative care programs exist. For example, "hospice care" in the U.S. involves mostly home care, whereas it represents an inpatient home-like setting in Canada and much of Europe. (Hui et al. 2012: 586)

As an example of the fourth possible reason that Hui et al. mentions, in the 1980s the term "terminal care" (*terminaalihoito*) was widely used in Finland for the care of dying. During the following decades, however, it was replaced with the term "hospice care" (*saattohoito*), and terminal care came to be considered insensitive (see the comment in ETENE 2004: 12). When going through the most recent professional literature in Finland, it can be noted that nowadays the term "end-of-life care" (*elämän loppuvaiheen hoito*) is preferred over "hospice care."

In addition to the actual differences in the meaning of the terms, there seems to be some variance also in the manner in which they are used. According to Bennett et al. (2010), most practicing healthcare professionals tend to use the terms "palliative medicine" or "palliative care" when referring to their clinical work, whereas "end-of-life care" seems to be more utilized by policy makers. In the public discussion in Finland, the term "hospice care" was widely used until recently—nowadays experts are using "end-of-life care" or "palliative care." [19]

[19] To some extent, it seems to depend on the discipline and the speaker's position which term—end-of-life care, palliative care, or hospice care—is used, and the use of the terms has changed according to the development of the field. During the years 2005–2015, there were as many references to hospice care in Finnish (*saattohoito*, 998 references in Google Scholar) as palliative care (*palliatiivinen hoito*, 994 references). Since 2015, there have

Furthermore, the professionals within hospice homes understandably talk more often about hospice care than palliative care. In regard to the actual care work in the field, these differences in semantics may be less significant, yet precise wording is necessary for legal purposes and rhetoric is also utilized in administrative guidelines and political agendas. In this way, the words used to categorize patients matter greatly.

The last remark in regard to definitions which I wish to make has to do with the actual verb 'to die.' According to Finnish law, a person is regarded as dead when "all of the brain functions have terminated permanently" (Finlex 27/2004, 2§). The definition appears simple, yet when the question is scrutinized more carefully, complex ontological and epistemological issues arise (DeGrazia 2017). Human death involves important questions in our understanding of what constitutes life in general and a human life in particular, such as what is personhood and what is the human connection with other life organisms (Kellehear 2008; DeGrazia 2017). Ultimately, as Kellehear (2008) remarks, even in the medical or legal profession, the determination of death itself is a social and cultural activity.

The verb 'to die' is complex to define. On a cellular level, our bodies are dying throughout our lives; in fact, this is necessary for our total organism to thrive (Vainio 2014). The question of death is interwoven with the question of life, and the interplay of these two are a continuous challenge for the natural scientists (Vainio 2014). When can we say that a person is dying? From a medical perspective, the question finds its answer from the body's physiological functions, and thus, in medical literature, the phase of "actively dying" has been defined as "the hours and days preceding imminent death during which time the patient's physiological functions wane" (Hui et al. 2014). From philosophical and sociological perspectives, the question of dying appears differently, and it is closely connected with given definitions for a "human" and a "person"—which ultimately are cultural constructions. For instance, we can differentiate a "social death" (Sudnow 1967) from a biological one: the concept of social death describes the "ways in which someone is treated as if they were dead or non-existent" (Borgstrom 2017). Understood in this way, social death can occur before or after the physiological death of a person.

The idea of social death can be also defined as "series of losses," such as "a loss of social identity, a loss of social connectedness, and losses associated with disintegration of the body" (Borgstrom 2017). Hence, the subjective experience of dying contains, and is constructed by, a variety of experiences, ranging from physiological to social, emotional, and existential. From a psychological or social perspective, the moment when these experiences begins is interpretable and highly subjective (Kellehear 2008). On one hand, people may experience themselves as if they were dying, whether from a medical perspective they were "actively dying" or not; on the

clearly been more references to palliative care (1,120) than to hospice care (827). For the general public in Finland, the term "hospice care" is still more recognizable than "palliative care." Finnish medical literature prefers the term "end-of-life care" over "hospice care" (Saarto 2019, personal communication).

other hand, they may be actively dying per the medical definition, yet they may not think of themselves as dying (Kellehear 2014: ix).

My research approaches dying from the first-person perspective. In the account of my research participants, these multiple facets (physical, social, psychological, or existential) of the end of life are interconnected. This study gives space for the first-person emic accounts and definitions of reality told by my research participants, yet as a scholarly work it also profits from etic concepts, definitions, and categorizations in order to interpret and deepen the understanding of these first-person accounts.

Reference techniques

In addition to the literary references, the study refers to my ethnographic research material (i.e., mostly the interviews and my field diaries). The interviews are referred to simply by the name of the interviewee and the ordinal number of the interview (for example, Aili/4). All of the interviewees have pseudonyms.[20] The research diaries (D) are referred to by their ordinal number and a page number (for example, D2: 16). Most of the time that I spend in the field, I did not have my recorder on; instead, I had my notebook on me all the time. In this way, some of the conversations ended up in my field diaries rather than on the recorder and in the transcribed interviews. When I took notes in the field, I paid very close attention to the wording of the research participants; consequently, some research diary references include exact quotations from the field.

I have translated all of the spoken quotes by my research participants from Finnish into English, and included the original Finnish expression only when the wording plays a significant role, or when the word choice by my research participant is somehow unusual. I have translated into English quotes from textual sources (such as blogs or poems, etc.) shared with me by the research participants, but I have included the original text in Finnish in the footnotes, with the exception of Inkeri's written text, since her text was not published (unlike the others) but it was a private work of art confined to my use.

[20] With the exception of the two bloggers, who wrote their blogs with their own names.

1.3 Introduction to death and dying in Finland

Death and dying in Finland

Finland is a Scandinavian welfare country with a relatively homogeneous population, compared to many other European countries (in 2015, only 6.2% of the population was of foreign origin (Suomen virallinen tilasto 2015). The country is very sparsely populated, and the population is largely concentrated in the south. Of its five and half million inhabitants, more than a million live in the Helsinki metropolitan area, where my research mostly concentrated.

Church membership in Finland has been traditionally high; still in 2000, more than 85% of Finns were members of the Lutheran Church. Although that number has declined over time, the strong legacy of the Lutheran Church is still visible, however, in various death-related practices, such as funerals, but also in the spiritual care within hospitals, which is most commonly offered in the form of Lutheran pastoral care (see Butters 2017).

About 54,000 people died in Finland in 2017, and the WHO has estimated that around 30,000 Finns are in need of palliative care every year, some at the end of their life and others already before that. Of these, approximately 40% are cancer patients. (WCPA & WHO 2014.) Finland's public healthcare system is complex and decentralized, and care is delivered in municipal, occupational, or private facilities (OECD & WHO 2017). The treatment is provided in either primary healthcare (which is often local) or specialized medical care (at hospitals), depending on the level of care needed. Due to the tax-financed healthcare system, patients can receive even the most specialized cancer care with very little cost.

Over the past thirty years, Western cultures have seen the beginning of a paradigm shift from extreme medicalization characterized by isolation and avoidance of death toward more holistic views of both health and healing and death and dying (Lewis [2006] 2011: 135–136; Kubsch et al. 2007; Utriainen 2010). In Finland, this shift became visible first in the funding of hospice homes run by non-profit private foundations, and then in the dynamic development of integrated palliative care in the field of public healthcare. The first national recommendations for hospice care in Finland were published in 2010 by the Ministry of Social Affairs and Health (STM 2010a).[21] In February 2016, the Ministry assigned an expert group with the task of drafting a proposal for the provision of palliative care and end-of-life care to ensure equal access to care throughout the country (Saarto 2017). These newer recommendations were based on a three-tier model for providing services at the basic, specialized, and intensive tertiary level of palliative care. Further recommendations were published in 2019 in a large report, in which recommendations on palliative care as a whole, based on quality criteria, were presented for each hospital catchment and district (Saarto & Finne-Soveri 2019). In addition, the latest report recommended that systematic basic education and supplementary and specialist training be organized for care professionals to address the skills gap in palliative care (Saarto & Finne-

[21] The first national memorandum about hospice care in Finland was published in 2003 by the National Advisory Board on Social Welfare and Health Care Ethics (ETENE 2003).

Soveri 2019). Related to this, in 2018 a new educational project called EduPal (funded by the Ministry of Education and Culture) was launched in order to develop palliative nursing and medical education through multi-disciplinary cooperation and working life collaboration (OKM 2018).

Since the 1980s, five hospices have been founded in Finland.[22] Since the 2010s, new palliative units and wards (with home care teams) have been opened in various hospitals around Finland, and palliative education has steadily grown (Saarto 2017; Saarto & Finne-Soveri 2019). Simultaneously, however, some of the hospice homes have faced serious economic challenges.[23] Although the general and geographical availability of palliative care has improved, in order to extend an equal level of services to the whole country, further improvements are still necessary (Saarto 2017; Saarto & Finne-Soveri 2019).

Suffering and the care of the dying

The general objectives of medicine are enhancing and maintaining health, preventing and curing diseases, and alleviating suffering (Lääkäriliitto 2019; Hallamaa 2019). Everyday medical praxis—and curative medicine by and large—concentrates mainly on the "curing diseases," whereas in palliative care the emphasis is on "alleviating suffering and pain." The challenge is that pain and suffering are understood to be subjective experiences, which cannot be so easily verified by quantitative medical tests. While there are various methods for assessing pain,[24] assessing suffering can be more confounding. Indeed, understanding and defining suffering have become major challenges in the realm of medicine.

There are numerous ways to define suffering in the medical context (Hänninen 2001). Eric Cassell (2004: 32–41), a well-known physician and oft-cited author on suffering, writes that *bodies* do not suffer, but *persons* do; suffering results not in the body or the psyche, but from a complex embodied entanglement of the person's whole life situation. Suffering happens in relation to the body and mind; in social, cultural, physical, and occupational contexts; and in one's transcendent ideas, past histories, plans, dreams, and hopes (Cassell 2004). The experience of suffering is subjective yet real, posing a challenge for science. Cassell (2004: 32) summarizes his definition by saying that suffering is "the state of severe distress associated with events that threaten the intactness of the person."

As (at least some degree of) suffering is nearly always associated with the end of life and dying, the crucial question in the care of dying people is how—and by whom—this suffering

[22] *Pirkanmaan hoitokoti* in Tampere (1988–), *Terhokoti* in Helsinki (1988–), *Karinakoti* in Turku (1994–2019, 2020–), *Koivikkokoti* in Hämeenlinna (2002–), and *Karjalakoti* in Lappeenranta (2011–2014).

[23] For instance, due to economic challenges, Karinakoti, which was run by the Cancer Society of Southwest Finland, was closed in 2019. After much political debate in the Turku municipality, the hospice home was reopened in 2020, but this time as part of the municipality's end-of-life care. Terhokoti in Helsinki has also had some challenges during the last years (HS 2014) and is undergoing staff reduction consultations as I write this in October 2020. Privately owned Karjalakoti functioned for only four years.

[24] These include the Visual Analogue Scale (VAS), Numerical Pain Rating Scale (NRS), and Verbal Rating Scale (VRS) (see Current Care Guidelines 2017).

should be recognized, assessed, and alleviated. Keeping the Physician's Oath in mind, the answer seems clear. Nevertheless, as Cassell has noted (2004: 31–32), while physical pain is something that physicians do treat, addressing suffering seems much more difficult in daily medical praxis. This is because, as mentioned above, suffering relates to persons (with histories, plans, dreams, relationships, etc.) instead of mere physical bodies as locations of diseases. Furthermore, Cassell has argued that "the training of physicians, their technical language, their diagnostic and therapeutic tools, and the economic forces that have become so dominant in medicine all focus on diseases, not patients" (Cassell 2004: 261).

Cassell reiterates here the classical argument presented in hospice philosophy already decades ago relating to the need of holistic care for dying patients. As the official guidelines of the Social and Health Ministry of Finland state, good palliative care should meet the patient's physical, psychological, social, spiritual, and existential needs (STM 2010a: 11). This statement conveys a metaphysical ideology with a certain kind of ethical understanding of reality and a metaphysical understanding of a human as a physical, psychological, social, and spiritual entity.

The question remains, however, how possible it is to bring and apply these ideals into the structures and practices of care. In the course of my ethnography, reflections of this ideology were visible in small everyday rituals of hospice, such as greeting the patient. Aili—the research participant with whom I had the longest relationship—was very impressed by the custom at the hospice home of hugging patients. She said it was the best thing at the day hospice: "The hug opens the day when we arrive and at the end of the day it sends us home" (D4: 15). This is one example of how experiences of the end of life became constituted via specific (care) practices located in certain places.

2. THEORETICAL DISCUSSION

2.1 Relational subjectivity

Subjectivity, intentionality, and experience

The study consists of three sections of analysis (Part II, Part III, and Part IV). The first section of the analysis (and the second part of the book), *The Disrupted Landscape*, concentrates on the moment of learning about the terminal diagnosis, and subsequently on questions related to orienting in a new landscape with death on the horizon. This section also discusses some matters concerning the care places where the research participants found themselves. Consequently, the first section of the analysis profits from theories that illuminate relational subjectivity and issues of spatiality.

As mentioned above, at the core of my theoretical and methodological analysis lies the notion of embodied subjectivity, which draws from phenomenological (Merleau-Ponty [1945] 2005; Utriainen 2000; Ihde 2002, 2009), postcolonial (Asad 1993), and posthumanist streams of thinking (Braidotti 2006, 2011, 2013; Sharon 2014). In mediated posthumanism, subjectivity is seen as generating and realizing itself in dynamic embodied relations with the environment.[25] The human being is not seen as a fixed, bounded entity separate from the external world, but rather as constituted through interrelations with the world. This perspective is of great importance to this study, since the way in which subjects are understood—that is, how they are understood to be constituted—naturally affects the way in which the process of dying is viewed. Because of this relational, embodied, and embedded perspective on subjectivity, I pay attention to the affective structures, practices, relations, environments, and people around the patients; how the patients experience all of the above and how these constitute the end of life; and also how patients negotiate their being-in-the-world-of-the-dying. In this way, in terms of theory, my study joints the current scholarly discussions on relationality and spatiality in regard to dying (Hockey et al. 2010; Ellis 2013, 2018; Christensen & Sandvik 2014; Seebach & Willerslev 2018; Borgstrom et al. 2019).

The dualistic perception of reality in terms of subject/object and interior/exterior has been challenged by many during the last decades, one of them being Merleau-Ponty in his book on the phenomenology of perception ([1945] 2005). Merleau-Ponty emphasized the bodily engagement we have with the world and its effect on our perceptual experience:

> As I contemplate the blue of the sky […] I do not possess it in thought […] it "thinks itself within me." I am the sky itself as it is drawn together and unified, and as it begins to exist for itself, my consciousness is saturated with this limitless blue. (Merleau-Ponty [1945] 2005: 249)

[25] This view follows philosopher Martin Heidegger's theory of the human Being as *Dasein*, that is, "constituted by its being in the world, by its engagement with worldly objects" (Sharon 2014: 140).

This quote illuminates the way in which people exist in the world, with the world, and of the world. This is precisely how I interpreted my research participants' experiences in their illness trajectories. Physical surroundings, medical staff, practices, aesthetics, bureaucracy, and so forth are not only structurally informative and socially constitutive for an experience of terminal illness, but they also comprise the experience in a sensorial, perceptual, and tactile manner. While criticizing the Cartesian dualism of mind and body, which does not respond to our experience of the world or of being-in-the-world, Merleau-Ponty claims that meanings are engendered in an entangled interconnection of subject and object (Merleau-Ponty [1945] 2005). This perspective grows in importance when one's body/mind becomes sick; the intertwining of mind, body, and the environment manifests itself in different ways at different stages of the illness.

According to philosopher of technoscience Don Ihde (2009: 9–10), it was John Dewey's pragmatism, however, that was the most successful theory in overcoming the subject/object dualism. In pragmatism, the emphasis is on what *happens*, not what *is* there. Since the focus shifts here from subjects and objects to verbs, we end up studying relationships.[26] It is about affective relationality constituting situational, transitory, yet dynamic subjects and objects in its course of actually happening. The study benefits from Dewey's ideas especially in regard to the aesthetic experiences outlined in Chapter 10.

The question of "experience"—what an experience is exactly—is a complex one. Anthropologist Jason Throop (2003) has pointed out that in regard to the centrality of the concept in anthropology, its exact epistemic and ontological definitions have been surprisingly little discussed. From a general phenomenological perspective, experience occurs when aspects of the world and the self come together in a manner that evokes emotions, ideas, and conscious intent in the subject (Dewey [1934] 2005: 36; Throop 2003).[27] This is, however, a problematic depiction for multiple reasons. First, it suggests a division between the subjective (consciousness) and objective (content) elements in the experience. This view was contested by William James and others studying experience, and it is problematic in phenomenology in general (see Throop 2003). Furthermore, as anthropologist Robert Desjarlais has noted, this kind of notion of experience is rooted in the idea of individual agency and reflective introspection, which are not always possible (Desjarlais 1994).[28] While it is difficult to find a precise definition for "experience," there are a few facets to it which are important to discuss. The first of them relates to the previous question of internality (subject) versus exteriority (object) and cognitive versus sensorial. In phenomenological theorizing, these categories are

[26] In a similar fashion, Heidegger emphasized the question of interconnected, complex, and open-ended being (as *Dasein*) rather than fixed, still existence as subject or object (Sharon 2014: 142).

[27] Dewey writes that "because of the interaction of live creatures and environing conditions," we are having experiences continuously: "Under conditions of resistance and conflict, aspects and elements of the self and the world that are implicated in this interaction qualify experience with emotions and ideas so that conscious intent emerges" (Dewey [1934] 2005: 36).

[28] For this reason, Desjarlais (1994, 1997), who studied homeless, mentally ill people in Boston in the 1990s, described them as "struggling along" rather than as "having experiences."

intertwined, even fused; that is the reason for the emphasis on the embodiedness, embeddedness, and relationality of experience. The other essential facet has to do with the element of time. In regard to time and experience, Desjarlais and Throop (2011: 88) write: "Our existence as humans is temporally structured in such a way that our past experience is always retained in a present moment that is feeding forward to anticipate future horizons of experience." The innate understanding of time is present in human experiences. For this reason, it is often thought that experience is akin to narration with a certain coherence and timely structure (Throop 2003: 233–234). But not all experiences render coherence. Throop (2003) distinguishes between the retrospective "ends" (that serve to structure the past lived experience) and the projected "ends" that arise in the immediacy of the present moment and which do not necessarily ensure experiential coherence. He continues:

> It is indeed in instances where our protentional horizon remains open, unfulfilled and/or discordant with an arising moment in the temporal flux that we fail to find our footing in the coherence of experience. During these moments there may be perceived breaks and disjunctions in our experience of lived temporality. (Throop 2003: 234)

Many of the moments that I observed with my research participants, or which they told me about, had this kind of open, fluctuating, and undetermined quality about them, thus making them kind of "vague experiences." Everyday life was mostly comprised of these kind of fractured undefined moments, yet at other times, I was told about clearly definite experiences. John Dewey has described the difference of these two by referring to *experiences* that occur all the time (life is constituted by a chain of experiences) and having *an* experience, which has a distinct quality of unity in itself (Dewey [1934] 2005: 36–37). In this study, the aesthetic experience that I talk about in the latter part of the dissertation is exactly this second kind, considered real experience by Dewey.

The last notion in regard to the phenomenological understanding of experience relates to intention. Intentionality refers to the human mind's tendency to be directed toward something; intent also ties past, present, and future together in regard to experiences. Death challenges intentionality, as there is no future to be directed toward. Here I refer especially to the kind of intentionality which Merleau-Ponty describes as operative intentionality. This intentionality is a kind of pre-reflective embodied relationality that a body has with the world and which "produces the natural and antepredicative unity of the world and of our life" (Merleau-Ponty [1945] 2005: xx). Operative intentionality is not of or about anything specific; rather, it is the relational mode of existence itself (Reuter 1999).

Relational living, relational dying

What lies at the basis of the contemporary perspectives, such as posthumanism, is that human experience is seen as "ontologically related to an environment or a world" (Ihde 2009: 23). The relationality is not only dynamic but also multidirectional in terms of a process in which all participants become transformed. Critical posthumanism takes a step away from the anthropocentric worldview by decentering the focus from humans and widening it to include various kinds of interrelated environments and relations between human and non-human agents (Braidotti 2013).

Akin to phenomenological and posthuman perspectives is philosopher Tamar Sharon's (2014: 135–171) theoretical formulation of "mediated posthumanism," which seeks to assess the relationality between human and non-human subjects, and specifically what that relationality means for the former. Embodied consciousness and embodied relational subjectivity are susceptible to transformation due to changes in the physical body/mind, such as its perceptual or kinesthetic capacities (Sharon 2014: 137–139). In other words, changes in physical conditions affect the ways in which subjectivity is experienced.

Many of my research participants increasingly as time went on lived in close connection with medical accessories and equipment (e.g., drugs, an intrathecal drug delivery device, an oxygen mask). These physical accessories affected the way in which the patients experienced themselves. Further, I interpret these apparatuses or actual medicines as endemic to one's existence. I do not see them merely as tools or means for existing, but rather I understand the subject (i.e., the patient) to exist in *an ontological relationship with them*.[29] As Sharon (2014: 101) puts it: "the human body/self and the construction of external and internal identity rely on technology." Or, as practical theologian Elaine Graham (2004: 27, cited in Sharon 2014: 102) writes: "to be human is already to be in a web of relationships, where our humanity can only be articulated – iterated – in and through our environment, our tools, our artifacts, and the networks of human and non-human life around us." Studying the contemporary manner of dying seems to defend this sort of interpretation of reality.

The coexistence with medical technology may become more visible toward the end of life. In general, technological devices ameliorate the quality of human life: one can see better with the help of glasses or move around easier with a help of a cane. Simultaneously, however, something in the subject has changed; for example, "an older woman" becomes "an older

[29] Philosopher and cognition scientist Andy Clark's book *Natural-born Cyborgs* (2003) is one of the earlier studies on medically and technologically enhanced humans, in which he writes on an example especially familiar to Finns: "Finnish youngsters have dubbed the cell phone 'kanny,' which means extension of the hand. The mobile is thus both something you use (as you use your hands to write) and something that is part of you. It is like a prosthetic limb over which you wield full and flexible control, and on which you eventually come to automatically rely in formulating and carrying out your daily goals and projects. Just as you take for granted your ability to use your vocal cords to speak to someone in the room beside you, you may take for granted your ability to use your thumbs-plus-mobile to send text to a distant lover. The phone really did seem to be part of the man, and the Finnish slang captures the mood" (Clark 2003: 9).

woman with a walker." Aili, one of my research participants, called her walker her "*kaveri*" ("buddy") and the young men I met on the oncology ward humorously called their intravenous (IV) stands their "*morsian*" ("bride").[30] When disease advances and the physical condition deteriorates, it is often the various biomedical aids that enable existence, admittedly to various degrees. Here the processual nature of living and dying becomes most visible. It is thanks to strong analgesics (pain relievers), for example, that the person is able to continue *being*, in the simplest sense of the word. For many, however, *being* equals *doing* (on body-in-action, see Irving 2017: 12), and when finding themselves in a situation where they are no longer able to do, they take this as the beginning of the end. Then, the actual dying—or *undoing*—starts.

In this way, medical reality mediates being. Biomedicine, including medical technologies, becomes part of us, whether we like it or not.[31] In this regard, I view medical "technologies of the self" (Foucault 1988) as an inescapable element of the subject. Rather than technology being merely "supplemental" or an "extension" of a human, the human can be seen more accurately as a result of this relationality with technology (Sharon 2014: 101).[32] Humanity can be understood as born of the interrelationality between the natural and technological environments, as well as between human and non-human others.

Yet, human-technological relationality, such as that seen in the case of biotechnology, can become problematic, as we will see in my research material. In order to avoid a simplistic approach to biomedical technology as something either positive or negative (e.g., Delaunay & Martins 2015), I find the approach of mediated posthumanism not only ontologically sound but also methodologically helpful.[33] Of course, medicine and technology were not the only kind of mediation that my analysis found from the research material. The approach of mediated posthumanism highlights the way in which my research participants experienced their illness, end of life, and dying via different kinds of mediations; the mediated nature of the experience became apparent also in the personal rituals and further aesthetic engagements that my analysis brought up. To summarize, mediated posthumanism equips me with an analytical attitude that is less burdened with value judgements, especially in relation to technology. Thus, "nature," "technology," and "human being" are not seen as different ontic essences but ultimately the same (i.e., monism).

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[30] I interviewed a few young men on the oncology ward, but since it turned out that they were not palliative patients, I did not include them in my actual analysis.

[31] Although people may believe that without chemical agents there exists some kind of "authentic" person, on closer scrutiny it is rather evident that this is a misconception. Since our being *in utero*, numerous chemical compounds are involved with our existence; we are affected and altered by them—whether in a medicinal way or otherwise—throughout our lives. The more that bioscience develops, the more there is an understanding of the miniscule biochemical elements of the body, such as DNA. This in turn makes it possible for medicine to ever more effectively enhance human capacities. It is the age of the molecular, as noted by Deleuze and Guattari (2016; see also Sharon 2014: 113).

[32] Here 'technology' can be defined as "the practical application of knowledge especially in a particular area" (Merriam-Webster 2020); medical technology can be anything from a plaster cast to modern imaging technology such as an MRI.

[33] On technological determinism in medical anthropology, see Timmermans & Berg 2003.

The following diagram (Figure 2, which will be elaborated at the end of this chapter) introduces the way in which the phenomenological approach and mediated posthumanism forms the core of the research: the phenomenological understanding of subjectivity and the mediated posthumanism as an approach to comprehend the relational and interdependent manner in which the research participants experienced their reality.

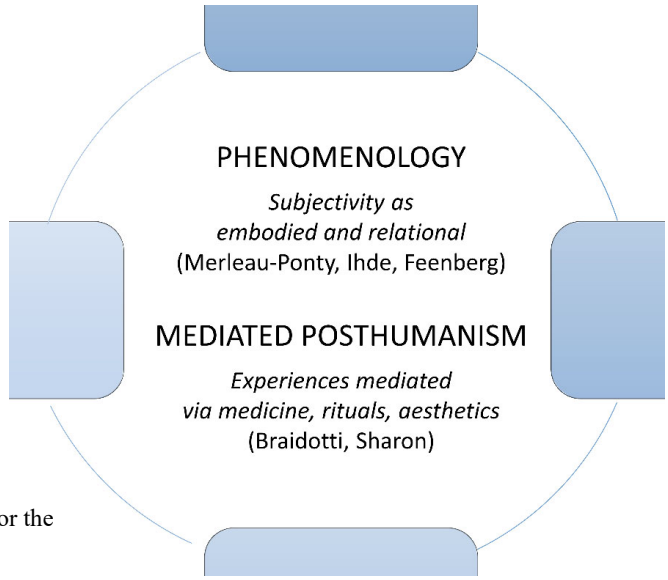


Figure 2. Core theoretical frame for the research.

Dying and the vulnerable body

In the center of the experience of illness and death is the body. One way to theoretically perceive the dying body is through phenomenological conceptualizations of it as multiple. Whereas there are many ways to describe the multiplicity of the body, Ihde (2002) introduces "body one" and "body two," in which body one is the *sensory body* that perceives, experiences, and senses life (the Merleau-Pontian center of the lifeworld) and body two is culturally and environmentally shaped and informed (and could also be called the "Foucauldian body").[34] This is not an unambiguous distinction, as body one and body two are naturally intertwined. Most of this study will concentrate on "body one," as I focus on the subjective lifeworld of my research participants; along the way, however, references will also be made to the "Foucauldian body" since most patients were objects of many kinds of physical manipulation which affected them in various ways.

Philosopher Andrew Feenberg (2006) criticizes Ihde's model for overemphasizing the activity of body, as if the direction of intentionality was always *from* the body as an initial center

[34] Ihde's conceptualization is akin to that of phenomenologist Drew Leder (1992), who wrote about two bodies in regard to medicine in his article "A tale of two bodies: The Cartesian corpse and the lived body."

of action toward the world.[35] Feenberg notes how embodied events and actions are multilayered, and they happen through complex communication between the body and the lifeworld. However, we can examine the general direction of the activities happening from, for, with, and within the body. Consequently, bodily experiences can be analyzed as subjectifying or objectifying, which renders the bodily experiences as more or less active or passive. Feenberg (2006) does this by adding two more bodies to Ihde's description of body one and body two—namely, body three and body four, respectively the "dependent body" and the "extended body." Both the dependent body and the extended body are of great relevance in a situation where the normal voluntary and involuntary functions of the body do not work as they did when one was healthy.

Feenberg's body three, the dependent body, is described in relation to the larger embodied being, who invites actions on it by others. Feenberg explains the dependent body through the example of a little boy who gets hurt in a football game and cries for help, rendering his dependent body as something for adults to take care of: "Inside our dependent body, we attend to unexpected sensations we have solicited. Our time horizon shrinks as we no longer control or plan the next sensation, yet we remain exquisitely alert" (Feenberg 2006: 190). As Feenberg notes, this way of experiencing corporeality often happens in medical situations, and nowadays it is actualized almost exclusively as a technological practice: "[W]e are operated on by a whole panoply of devices. From the users of tools we become the object of tools" (Feenberg 2006: 190).

In this study, I examine how these situations feel for the actual person experiencing them, in order to gain a deeper understanding of "our lived first-person experience of our own instrumentalized status" (Feenberg 2006: 190). Feenberg differentiates the dependent body from the Foucauldian political body positioned in a web of exercised power.[36] According to Feenberg, the dependent body quite voluntarily invites actions on itself, but at any given moment, it can reverse the passivity and take control again. I am not convinced about Feenberg's claim of a reversal in such a simple manner as he suggests. Having entered into an embodied relationship with medical authorities, the patient's situation becomes complex in a number of ways. There are different factors at play, not just bodily ones. In order to be able to assume the mode of the dependent body, there needs to be trust—not just trust with medical personnel, the fellow humans into whose hands we literally commit our bodies, but also trust in biomedicine's epistemic and ethical goals as well as an understanding of the whole existential

[35] Feenberg (2006: 189) notes that because of Ihde's "orientation toward scientific perception and technical action," he focuses too much on "the extension of the senses by scientific instrumentation, computer simulations, and virtual reality," and ultimately this leads Ihde to bypass the passive aspects of the body.

[36] For Foucault, a human body is essentially always also a political body infused in various sorts of practices of power: "[…] the body is also directly involved in a political field; power relations have an immediate hold upon it; they invest it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs (Foucault [1977] 1995: 25).

situation in general. I would argue further that power is always an issue here (Turner 1995). As Bell (2009: 203) writes (in reference to philosopher Michel Foucault): "the body is the 'microphysics' of the 'micropolitics' of power."[37] In the end, some of the things that I learned during my fieldwork had to do exactly with this collision between Feenberg's dependent body and the Foucauldian body as a center of practices of power.

This vulnerable aspect of the body can also be approached from the point of view of self-identity, as explained by sociologist Anthony Giddens ([1991] 2006). According to Giddens ([1991] 2006: 52–54), self-identity presumes reflexive awareness, and it is based on "a capacity to keep a particular narrative going" (Giddens [1991] 2006: 54). Self-identity is not to be found in behavior, nor is it a collection of traits. Rather, "it is the self as reflexively understood by the person in terms of her or his biography" (Giddens [1991] 2006: 53). Self-identity is dynamic since one has to adapt to and continuously integrate external events into one's "ongoing 'story' about the self" (Giddens [1991] 2006: 54). Giddens notes that the "contents" of self-identity—traits from which biographies are constructed—vary socially and culturally. In "Western" advanced capitalism, the autonomous and independent self, including an independent body, is highly idealized. Therefore, the change from an independent to a dependent body can cause intense crisis in self-identity, leading to "ontological insecurity," as Giddens puts it ([1991] 2006: 57–58). All individuals become vulnerable if—or, more accurately, when—their competence to continue "bodily self-management" breaks down at some point in life.

My analysis will also make a reference to Feenberg's body four, namely, the extended body. Here technical enhancements act as extensions of the body, but instead of focusing on the corporeal experience of these sensorial extensions, Feenberg looks at how these extensions function as ways to objectify ourselves to others (i.e., what these extensions of the body signal to others). As an example, Feenberg (2006: 193) refers to computer usage and, more specifically, online communities, which, he claims, are all too often dismissed simply as forms of disembodiment. For Feenberg, online communities offer a platform for textual self-presentation; the used language, images, memes, avatars, and so forth are ways in which people can objectify themselves to others. As a parallel to the actual physical extensions, such as clothes and accessories, Feenberg writes that "we could be said to 'wear' language online in something like the sense in which we wear cloths in everyday life. It is a form of *virtual*

[37] In *Discipline and Punish*, Foucault writes: "Now, the study of this micro-physics presupposes that the power exercised on the body is conceived not as a property, but as a strategy, that its effects of domination are attributed not to 'appropriation,' but to dispositions, manoeuvres, tactics, techniques, functionings; that one should decipher in it a network of relations, constantly in tension, in activity, rather than a privilege that one might possess […]. In short this power is exercised rather than possessed. […] Furthermore, this power is not exercised simply as an obligation or a prohibition on those who 'do not have it'; it invests them, is transmitted by them and through them; it exerts pressure upon them, just as they themselves, in their struggle against it, resist the grip it has on them. This means that these relations go right down into the depths of society […]" (Foucault [1977] 1995: 26–27). In short, Foucault saw power as a strategy which is exercised in and spread throughout the various (institutional) relations in society, and which affects people's bodies and behavior in a complex manner.

embodiment…" (Feenberg 2006: 193, italics mine). This perspective regarding one's existence becomes helpful when I analyze blog writing as a contemporary ritual around death.

2.2 Space and emotion

Landscape: On the question of spatiality

Due to the emphasis on relationality in my study, questions of *space* and *place* become important. Spatiality and temporality are essential facets of all human experience.[38] Yet, the issue of a place becomes utterly important when one's body starts slowing down and eventually hinders spatial bodily movement—and the capacity to change the environment at will. Once one's bodily autonomy becomes severely reduced, dependency on the environment—other sentient beings, technology, and materiality, as well as practices and relationships—grows considerably.

I use the word *landscape* in both a metaphorical and concrete sense in order to refer to cultural and personal spaces and places at the end of life and when dying. In this way, the notion of landscape works as a factual reference to the various places and situations in which my research patients found themselves. I will also occasionally use the notion of deathscape, which refers to specific sites and spaces related to death (Maddrell & Sidaway 2010),[39] yet to my mind the notion of deathscape relates more to the deceased and rituals of remembrance rather than the dynamics of living the end of life or the process of dying; thus, here I prefer the dynamic notion of landscape.

Taking a spatial approach to dying implies further questions on materiality; hence, the recent interest in spatiality coincides with the current attention to new materialism and affect in the study of religion (e.g., Houtman & Meyer 2012; Schaefer 2015; Hutchings 2017), as well as with studies of senses and atmospheres in anthropology (Pink 2015; Sumartojo & Pink 2018). The "spatial turn" (Warf & Arias 2008) has also affected contemporary nursing science and research on care, resulting in a variety of studies concerned with space, such as how the nursing environment is experienced aesthetically by patients and nurses (Aaltonen et al. 2016; for a literary view on the topic, see Apell & Mattila 2017). In the study of religion, spatial concepts of place, space, and landscape have important sociocultural, psychological, and metaphysical meanings, and over the last ten years there has been growing interest in the field (Knott 2010).

[38] Until recently, the temporality and historicity of social life seem to have attracted researchers' attention more than issues relating to space (Soja 1985; Borch 2002; Casey 2013: 10). However, since the development of human geography (Harvey 1969, 1989; Tuan [1977] 2001; Massey 1977, 2005; Soja 1985, 1989; Thrift 2008), there has been growing interest in spatiality in the humanities and social sciences (Saarikangas 2006; Pink 2015; Beebe, Davis & Gleadle 2012).

[39] The notion of deathscape, which was originally introduced by Lily Kong (1999) in the field of cultural geography when studying cemeteries and columbaries as landscapes of death, has been popular in recent spatial studies in relation to death and dying (Maddrell & Sidaway 2010: 4). From being first a notion on landscapes and concrete geographies, the term has since grown to more broadly become an analytical tool with various applications. In their edited publication on deathscapes, Maddrell & Sidaway (2010) summarize their usage of the word as invoking "both the places associated with death and for the dead, and how these are imbued with meanings and associations" (Maddrell & Sidaway 2010: 4).

In regard to the difference between space and a place, the former is often considered as a more abstract concept than a place; conversely, a place can be thought of as a specific location or a portion of space (Casey 2013: 337–338). In addition to architecture and geography, the concept of place has inspired research in relation to memory studies and identity (Perkins & Thorns 2011). As a lived location in space, a place is often related to histories and therefore also to emotions and affect. This sense of spatiality becomes visible in the stories that my research participants shared about the places which they longed for, which they missed, or which represented the heart of their hopes and dreams (see Chapter 10). Furthermore, space is understood to be an active physical, mental, and social factor, creating not only inner experiences (Tuan [1977] 2001) but also social relations and power dynamics (Harvey 1969, 1989; Lefebvre 1974; Soja 1985).

Sickness and dying integrate the societal and institutional orders of reality with the most private and personal aspects (Lämsä 2013); therefore, when seeking to make sense of patients' experiences, one has to allow both personal and institutional elements to surface. This is the reason why my analysis so deeply involves the various aspects of spatiality, be they concrete and physical, imagined and mental, or structural and bureaucratic.[40] Both critical social analysis of space and the phenomenological tradition of studying the spatiality of the human experience (such as offered by Chinese-American humanistic geographer Yi-Fu Tuan ([1977] 2001) are of great value here.

As philosopher Henri Lefebvre (1974) points out, both physical location and relationalities (e.g., policies, practices, beliefs, attitudes, and people) affect and create different kinds of spaces. In this case, the relationships that patients had with their surroundings became crucial to their comfort and wellbeing. When the ethnography revealed the importance of these relationships, it drove me to inquire how these (care) environments became constructed, and how patients ended up in certain care places over others. In reality, this process is directly affected by national and local recommendations, policies, and practices in regard to palliative care and end-of-life care. Accordingly, learning about care policies and practices became part of my dissertation work (see the discussion in Jenkins et al. 2005: 12–13).

Spatial issues around death have arisen in the recent studies emphasizing the materiality of lifeworlds. In an edited volume *The Matter of Death: Space, Place and Materiality* (2010), social historian Ken Worpole and medical sociologist Carol Komaromy looked at the different places and spaces for dying, such as nursing homes and hospices, from functional, operational,

[40] In regard to physical space, according to the most recent care policy (Act on Elderly Service 2012; THL 2017), the care of the elderly and chronically ill is to be (re)located into people's homes rather than care facilities, including elderly homes. Consequently, as the care of the dying should be done "wherever the person has been taken care of heretofore" (THL 2016), more people ought to be dying at home. So far, however, this has remained an ideal. In reality, approximately 70–80% of dying people move, or are moved, away from their prior living environment into a care facility, most often into a ward at the local healthcare center (THL 2016). Moving prior to (and sometimes even during) the moment of active dying is often unnecessary from the perspective of care and almost always emotionally charged (for both the dying and their loved ones). Nevertheless, it still often happens.

and architectural points of view in order to understand how living and dying were made possible there. In my study, I put emphasis on understanding how patients themselves related to the place in which they were (or had been previously), and the ways in which they connected with or disconnected from their surroundings. What does the place of dying mean for the dying person—or does it mean anything?[41] I listened to the patients about their experiences, wishes, hopes, and disillusionment about the places they needed or wanted to be in. Along with actual places, there were also virtual spaces and places that held importance, whether they became actualized or not (Kapferer & Hobart 2004; Kapferer 2006, 2010).

Striated and smooth: Analysis of the space and practice

As mentioned already above, studying the lifeworld of the dying person elicits questions about such dichotomies as body/mind or, in relation to space, internal/external. While problematizing commonly used binaries is part of the overall theoretical conversation of this study, doing this—especially in relation to internal/external—also simulates the lifeworld of the dying. Even if we were to ontologically deny the dualistic nature of existence, representing the world through binaries appears to be tightly bound to the "Western" model of metaphysics and the commonplace manner of thinking about reality. In proximity to death, however, the collapse of orderly reality—with seemingly self-evident categorizations such as internal/external, self/other, and body/mind—seems to be rather typical. How does this happen? How do dying people experience themselves in their milieu?

One way to approach such commonly viewed dichotomies is via the concepts of *smooth* and *striated*, which were introduced by French philosophers Gilles Deleuze and Félix Guattari in their book *Mille Plateaux* (1980). Deleuze and Guattari used these concepts in order to describe the different ways of elements coming together to form dissimilar spaces. In the natural world, for instance, smooth space is described to be the one inhabited by nomads and mariners going with the flow of nature, adapting to the weather, whereas striated space is the one conquered by farmers, who shape and adapt the land to their needs. Smooth and striated not only depict spaces; they can be descriptive for a variety of things, such as materials, technologies, musical models, or ways of thinking and doing science. Smooth and striated space are of different natures and sometimes even oppositional. Yet, Deleuze and Guattari (2016: 552) emphasize that "in fact the two spaces exist only in mixture: smooth space is constantly being translated, transversed into a striated space; striated space is constantly reversed, returned to a smooth space." This dynamic and processual aspect of reality is important to keep in mind.

Deleuze and Guattari were interested in the possible processes that entities are involved in; with a conceptual pair such as smooth and striated, we can investigate not what something is

[41] This aspect of the study was impacted by the research design and the type of research permission I was given. Thus, I did not personally study all of the places I was told about, yet sometimes I was actually present at the place at the moment (which the research participants were referring to) and able to make some observations. On many occasions, however, the narratives concerned past experiences or future hopes. In sum, I studied people's experiences, wishes, disappointments, and so forth in relation to places and spaces.

but "what it *does* or *might do*, and how it might affect what other things do and how it might be affected by them" (Abrahams 2013: 4). As different modes of spatialization, striated and smooth *do* things; they affect and they are affected, and thus they are useful in regard to the analysis of the relations between the medical world and realities of illness. Bringing the idea of striated and smooth space into my analysis of the environments of dying people allows insight into how different environments construct and compose patients and death in different ways, as well as how patients and medical personnel engage in actions which transform the spaces from one type into another.[42]

Joy and sadness: Spinozian understandings of emotions and power

When studying the way in which particular relationalities affect the patients' experiences of their end of life, I draw from Baruch Spinoza, an early modern Dutch philosopher (1632–1677), who has inspired in the last decades some poststructuralist and posthuman philosophers (e.g., Deleuze 2001; Braidotti 2011), as well as some neuroscientists (e.g., Damásio 2003). My understanding of Spinoza is affected by Deleuze's reading of his work, as well as the new materialist take on his writings, such as the one developed by posthumanist philosopher Rosi Braidotti (2011).

Spinoza's theory on emotions offers a sophisticated and useful way of understanding people's emotional experiences. The manner in which he links one's emotions and one's ability to think and act offers one insightful way to understand the effectiveness and importance of emotions in our daily life. Moreover, the way that Spinoza conceptualizes a difference between active versus passive emotions enables us to better comprehend their complexity (e.g., how it is possible for some to experience joy even in very difficult and sad situations).

Due to Spinoza's monism, the connectedness of body and mind is of utmost importance in his thinking. In Spinoza's system (which includes one substance, an infinite number of attributes, and finite and infinite modes), a human is defined as a finite mode living in a complex web of relationships in an environment filled with other finite modes, be they material or immaterial (Pietarinen 1993: 37). Due to *conatus*, which is a sort of basic vitality or life force pertaining to all bodies, every being seeks existence and aims toward active participation in the world (Pietarinen 1993: 38–39). Because of the priority of relationality as the basis of human life, the idea of affects (or emotions) becomes critical in explaining the workings of this relationality.

Spinoza separates affections (Lat. *affectio* traditionally translated as "effects") and affects (Lat. *affectus* traditionally translated as "emotions") from each other (Lloyd 1996: 72; Deleuze

[42] This is not the first time that Deleuze and Guattari's spatial concepts are employed in a theoretical conversation seeking to understand the different contexts and networks that are built around patients in medical environments (see, e.g., Walsh 2012a, 2012b; Bleakley 2013).

2001, 2007).[43] Since we are always already in the world we are subsequently always affected by the world—and thus having affections, which can be understood as various kinds of bodily states manifested within us. Philosopher Genevieve Lloyd, a contemporary Spinozist, explains, "*Affectio* is a state of the affected body, implying the presence of an affecting one" (Lloyd 1996: 72). Now, the interesting feature of Spinoza's theory—and the most important one in regard to this study—is the way in which he connects emotions with agency. Spinoza calls affects (or emotions) the kind of affections which either increase or diminish our power to act (*Ethics*, Part III, Definition 3, in Spinoza & Parkinson 2000; Lloyd 1996: 72). In short, for Spinoza, affection (*affectio*) is about the embodied relational mode of being in relation to the world and affect or emotion (*affectus*) is a special type of it. There are three main emotions: *conatus*, which serves as a basis for the striving for existence, *laetitia* (joy), and *tristitia* (sadness). All other emotions are derivatives of the main affects of joy and sadness. For Spinoza, *affects or emotions are about movement toward either a greater or lesser ability to act and think*. The facet of the theory that is especially helpful here is the way in which Spinoza explains *laetitia* and *tristitia*: Spinozian joy increases our capacity to act, whereas sadness respectively decreases our capacity to act. These emotions happen in both the body and mind: "Whatever increases or diminishes, helps or hinders our body's power of acting, the idea of the same thing increases or diminishes, helps or hinders our mind's power of thinking" (*Ethics*, Part III, Proposition 11, in Spinoza & Parkinson 2000). In other words, various forms of *laetitia* increase our inner activity and strengthen our sense of connectedness and openness to the world, whereas negative affects of *tristitia* decrease our inner vitality and engagement with the world. Experienced by individuals, affects are born from our encounters with the world; conversely, they also influence the way we encounter, or are able to encounter, the world.

Humans do not respond to outer influences in some automatic way. The degree of effect that these outer influences can have on us, be they positive or negative, depends on our *conatus*, the innate vitality and affirmative will to exist, to participate in the world, and to be open to life. Furthermore, all affects, both joyful and sad, can be experienced either passively as passions (Lat. *passio*) or actively as actions (Lat. *actio*). Spinoza claims that whenever we have a clear,

[43] Here it is important to briefly note the general discussion on affect and emotion which has been ongoing for the last twenty years (for instance, in philosophy see Massumi 2002; in the study of religion, see Schaefer 2015; in anthropology, see Lutz 2017; in sociology, see von Scheve 2018). The variety of perspectives in relation to the different disciplines involved has produced different kinds of understandings of what affect is, and whether it should or should not be distinguished from emotion. In recent cultural studies, it is common to see affect as an immediate, preconceptual, relational bodily state or "intensities" (Massumi 2002: 27), while emotions are identified, conceptualized, and categorized subjective experiences (Paasonen 2017). Furthermore, it is often explained that there are no personal feelings or sentiments in Spinozian affect (Massumi 2002). One way to differentiate between feelings, emotions, and affect is to relate feelings with the personal and biographical, emotions with the social, and affect with the prepersonal (Shouse 2005). In practice, however, affect and emotion seem to be intertwined in such a way that it becomes impossible to differentiate them (Paasonen 2017). I could easily subscribe to this kind of conceptual differentiation between affect and emotion, yet it does not correspond to Spinoza's original thinking (from which many contemporary scholars have drawn their ideas) (Kristensen 2016). For the purpose of this work, I will use the concepts of affect and emotion somewhat interchangeably (see also Lutz 2017).

"adequate" idea of what it is that is affecting us, we respond actively; whenever our understanding of the world and the causes affecting us remain hazy and unclear, or "inadequate," we have passions and are able to only react, rather than act within the world (Toivoniemi 2015). This means that joy, for instance, is not always active. When the reason for joy remains unclear to us, we are experiencing passive joy, but when we gain clarity into the causes behind our emotion, it becomes active. There is no active sadness, however. When we become aware of the causes of our sadness, and gain a clear understanding of them, the passivity of the sadness ceases, but since this understanding increases our power and ability to act and think, the emotion starts to generate joy (Carlisle 2011). In this way, in a Spinozian world, it should be possible to take the causes of sadness, accept them, and start acting from the basis of that acknowledgement.

It is key to note that for Spinoza, affects as emotions are not strictly about how they *feel* to the subject but rather how they *function* in regard to the subject's power of acting (Deleuze 2007). If we choose to look at emotions in this way, it is possible to analyze the complex relationality and interconnectedness of patients with their environment, which so greatly impacts the experiences that dying patients have during their last weeks and months (see Lawton & Nahemow 1973, cited in Kotilainen 2014). Even though some scholars, such as philosopher Brian Massumi (2002: 27–28), situate affect prior to the distinction of negative (sadness) or positive (joy), I find the Spinozian theory of negative and positive emotions to be useful, since it illuminates the connection that affect has with power: the power to affect and the power to be affected, that is, power as *potentia* or as *potesta* (Large 2013). Because the causes of sadness (illness and imminent death) exist, the important question is how these causes affect oneself and one's power to act and think. The Spinozian perspective equips me with tools to analyze people's situations in regard to increasing or decreasing power. As Deleuze says in his lectures on Spinoza in 1978:

> Spinoza doesn't make up a morality, for a very simply reason: he never asks what we must do, he always asks what we are capable of, what's in our power, ethics is a problem of power, never a problem of duty. In this sense Spinoza is profoundly immoral. Regarding the moral problem, good and evil, he has a happy nature because he doesn't even comprehend what this means. What he comprehends are good encounters, bad encounters, increases and diminutions of power. Thus he makes an ethics and not at all a morality. (Deleuze 2007: n.p.)

Instead of making allegations or evaluations about things being "good" or "bad" in themselves, the Deleuzian take on Spinoza's ethics allows me to analyze the encounters that patients had with their environment in terms of an increase or decrease of their power to act and think. Per Deleuze, Spinoza was averse to any philosophical tradition which focused on "meditations on death," since for him philosophy was about life. As Deleuze (2007: n.p.) points out, "death is always a bad encounter."

2.3 Theoretical discussion on practices vis-à-vis death and dying

Ritual perspective on practices at the end of life

The second part of the analysis (and the third part of the book), *Institutional Rituals and Practices*, starts by focusing on the variety of actions in which the research participants engaged; when analyzing actions, ritual studies become an important point of reference. This is not only because rituals are a classic way of negotiating death, dying, and mourning, but also because by studying practices from a ritual point of view, it is possible to reveal attitudes and assumptions which could otherwise remain hidden. There are always some metaphysical perspectives embedded in rituals, either implicitly or explicitly, although rituals can simultaneously assert and create a world-ordering in their own right (Bell 2009: 195). I find ritual practices and ritualizations to be an insightful way of looking at contemporary understandings and ideas of death and dying.

As an anthropological term, "ritual" has multiple definitions (Bell [1992] 2009). While anthropological theorizing has produced different understandings of ritual over the decades, a common element among them is that either they regard ritual as separate from mental categories (as action is separated from thought and belief) or ritual is seen as a type of functional or structural mechanism to integrate the thought-action dichotomy (Bell [1992] 2009: 20). My understanding of ritual follows the latter. The view of ritual action entwined with thought and belief is congruent with phenomenological notions of the inseparable nature of the body/mind. Furthermore, as philosopher Mark Johnson has argued, all human understanding and reasoning are *embodied activities*, as we make sense of the world in a corporeal manner, via our bodies (Johnson 2007: 279–280). In this way, I see that rituals involve both doing and thinking.

Here 'ritual' can be defined as a *(symbolic) activity that aims to organize a participant's social and metaphysical reality by guiding cognition and channeling emotion*s (applied from Snoek 2006: 11). Often ritual is thought to function as a "vehicle for the creation and transmission of cultural meaning" (Salhi 2016: 210). In turn, 'ritualization' describes the process in which a practice transforms into a ritual; in this way, it may refer to a smaller, less-defined everyday ritual. As scholar of religious studies and renowned ritual theorist Catherine Bell writes: "ritualization is a way of acting that is designed and orchestrated to distinguish and privilege what is being done in comparison to other, usually more quotidian, activities" (Bell [1992] 2009: 74).

In regard to my study, at the beginning of the project I was interested in learning if there was any religious or spiritual rituals around death in contemporary Finland. This proved to more complex than I had foreseen, since, to my surprise, finding patients who would even identify themselves as dying was not so easy—even amongst the hospice patients. If I had imagined that upon learning about their terminal diagnosis people would start preparing for the end of life and death, for the most part I was mistaken. Instead, I tended to encounter patients who were

continuing to fight for another month, week, or even a day.[44] I came to think of this not so much as a matter of *denial* of death (Kübler-Ross [1969] 2009), but rather as an *avoidance* of death. I interpreted this line of thinking and acting as attempts to reinforce life and living as the norm and the assumed mode of being. Here, terminal illness appeared as a threat to be fought against. In this way, many of the daily efforts were aimed at staying alive, not preparations for dying in some particular manner or in some certain place, for example. I began to consider the tenacious efforts to stay alive as *rituals for avoidance of death*. This also led me to analyze medicine from a ritual point of view.

Rituals in regard to healing and mourning are perhaps the most classic anthropological topics of study (e.g., Turner 1961, 1970; Kapferer [1987] 1991; Desjarlais 1992, 2016; Csordas 1997; Jenkins, Jessen & Steffen 2005). Curing, healing, and mourning as rituals have also been studied within contemporary medical institutions. In the recent research conducted by scholars from various disciplinary backgrounds, ritual has been understood in multiple ways, at times normatively. Ritual has been approached pejoratively as a practice that is empty of meaning in regard to medical utility, yet on the other hand rituals have been found to be therapeutically or psychologically valuable and thus useful in relation to patient care and the practice of the art of medicine (e.g., Elks 1996; Philpin 2002).[45] While rituals of care have been studied mostly in the field of nursing science (e.g., Walsh & Ford 1989; Woodhead 2002; Wolf 2014), the significance of ritual in relation to the placebo effect occupies its own scholarly discussion in the fields of medicine and anthropology (Welch 2003; Brody 2010; Kaptchuk 2011). In regard to this study, as an anthropologist and scholar of the study of religion I approached the medical world as a cultural phenomenon, and I attended to the cultural and social aspects of medical practices.

From the anthropological point of view it could be said that ritual pervades medical practice; ritual elements can be found in medicine's specialized terminology and procedure, and in ritualized space; even the apprenticeship of medicine is highly ritualized (Salhi 2016). Subsequently, as a site for various kinds of social constructions, including rituals, the medical world has been a topic of sociological and anthropological studies for decades (Foucault 1963; Glaser & Strauss 1965; Sudnow 1967; Peräkylä 1988, 1989, 1990; Kaptchuk 2011; Costanzo & Verghese 2018). Hospital rituals have been studied in sociology, medical anthropology, and philosophy (Davis-Floyd 1992; van der Geest 2005; Brody 2010; Kaptchuk 2011), in nursing science (Wolf 2014), and even in medical studies (Bosk 1980; Welch 2003). Rituals which have to do with the socialization of a person into the role of a patient, for instance, are well known

[44] In the introduction to his book *The Inner Life of the Dying Person*, Kellehear (2011: ix) mentions "the increasing number of people who have advanced disease, commonly a spreading cancer, who will not acknowledge to themselves any notions of death or dying." These people may be medically dying but they aspire to be "survivors to the end"; they are not dying but living with chronic disease (Kellehear 2011: ix).

[45] On the usefulness versus inutility of rituals in hospitals, see Risse 2014; for a discussion of the ritualized nature of evidence-based medicine, see Knott & Franks 2007. Nursing scientist Susan Philpin (2002) also has an insightful article on the variety of interpretations given to medical and nursing rituals in the social and nursing sciences.

(Holland 1993; Wicker 1999; Woodhead et al. 2002; Wolf 2014). Medical clinics and institutions such as acute care facilities and operating rooms, or hospices and care homes, can be anthropologically approached as liminal social sites in which significant transformations and rites of passage happen (Davis-Floyd 1992; Gordon 2015). In this way, birthing, curing, healing, aging, and dying are interpreted as institutionalized moments shaping various life-cycle becomings.

The entire daily rhythm of the hospital ward is heavily ritualized in terms of communication, hierarchical relationships, staff clothing, and so forth (Risse 2014; Lämsä 2013). In the medical world, rituals are often related to matters of safety; for instance, the ritualized checklists in the operation room are all about following safety protocols, and regular routines in hospital wards have been regarded as creating an atmosphere of control and security for patients and caregivers alike (Risse 2014: 18). Ritualized and routinized manners of performing medical and nursing tasks can alleviate stress and anxiety related to them, and they enable the practitioners to perform tasks that otherwise might "provoke emotions of embarrassment, fear, fascination, and disgust" (Katz 1981: 345 cited in Philpin 2002: 150). Furthermore, rituals in medical surroundings have importance for maintenance of social order, especially in situations of ambiguity (Philpin 2002).

My decision to call some medical treatments rituals could be critiqued by claiming that by doing so, I divert attention away from the medical purpose and intention of the treatment. I argue against this. Treating medical practices as rituals does not reduce their medical significance; it merely adds another layer of possible cultural, social, psychological, and metaphysical meanings attached to them.[46] In the following chapters, therefore, I describe how in actuality medical practices are never only about medicine (Elks 1996; Tercier 2005; Mohammed & Peter 2009; Brody 2010; Wolf 2014; Gordon 2015).[47] Since the focus of my study revolves around the patient, I studied how certain medical practices functioned as rituals and how patients perhaps used them for their own purposes in relation to their existential situation.[48] In a society where religious doing (i.e., religious rituals) is not necessarily part of the prevailing practices, medicine can gain an existential position: medical treatments can become rituals that people invest in when seeking solutions for existential troubles (Brody 2010; Gordon 2015).

[46] On medicinal pills as rituals, for example, see Brody 2010.

[47] Some scholars have argued that at times, medical practices are not even about medicine; for instance, medical procedures such as resuscitation are not always performed so much as an attempt to save the patient's life but to produce a medically controlled death, which is also easier for the bereaved to accept (Pagie 2010; Mohammed & Peter 2009; see also Seale 1998: 79–80).

[48] Although occasionally it did happen, generally the research participants themselves did not talk about their activities as "rituals." However, the way in which they practiced and talked about certain things—such as medicine, for instance—revealed ritualization; the practices began to have meanings and values other than those strictly related to health. In other words, they began to "organize a participant's social and metaphysical reality by guiding cognition and channeling emotions" (see Snoek 2006: 11).

Medical practices were not the only ritualized practices at the end of life, however. By using the perspective of ritual in relation to my research material, I was able to look at various—and very different—kinds of practices done for or by terminally ill patients, which implicated some social or cultural meaning or value beyond the obvious. These ritual practices, be they medical treatment, alternative healing therapy, special food regimens, or vitamin supplements, created a kind of virtual—or subjunctive, as some scholars would say (Utriainen 2016, 2020)—reality, filled with affective *hope*. In this hopeful virtuality, transformation (curing and/or healing) could happen, and one could free oneself, even if momentarily, from the chaotic presence of the terminal illness by seeking some control over the situation (Kapferer 2004, 2006: 671). On many occasions, rituals appeared as affective practices seeking to assert agency and used to establish control over a situation otherwise perhaps difficult to deal with. Furthermore, rituals can have meaningful performative and expressive goals of their own (Tambiah 1968, 1979; Bell [1992] 2009: 19–29, [1997] 2009: 131–136).

Ritual metaphysics

Death rituals often include explicit statements about the world, the nature of reality, and the dying/dead person's place in it—in other words, death rituals tend to be strongly related to metaphysics. Medical practices and rituals that define sickness (versus health) or death (versus life) are equally based on some theory about life, including a metaphysical understanding of "what is a human." The question of *who* gets to define the reality in ritual is, of course, a crucial one for the ritual participants. This is connected to issues of agency.

In regard to the matter of agency in ritual, philosopher Kevin Schilbrack (2004) makes a distinction between philosophical subjects and philosophical objects. Per Schilbrack, the ritual participants are mainly in the position of philosophical objects when they are being "inscribed with" metaphysical, social, and affective ideals and meanings in the course of the ritual. However, as Bell (2009: 191–196) has argued, rituals do not mechanically insert or ascribe anything onto ritual participants; rather, when participants adopt meanings during rituals, they do it by appropriating, negotiating, and qualifying the ideas and beliefs presented to them, and they may also reject and resist the "inscriptions." Since Schilbrack's way of using the notions of subject and object is somewhat problematic, I suggest that his subject/object categorization should not be taken as rigid or mutually exclusive, for in practice one may find oneself in both positions simultaneously. Nevertheless, his theory on ritual metaphysics offers insight when seeking to understand the relationship of metaphysical thinking and rituals.

Schilbrack continues by explaining that when the participant is in the position of a philosophical subject, as an active subject of experience, the ritual becomes a form of an inquiry and a source of knowledge for the participant (Schilbrack 2004: 135). Here Schilbrack follows anthropologist Theodore Jennings' (1982) idea of ritual as a mode of "coming to know":

> Ritual knowledge is gained through a bodily action which alters the world or the place of the ritual participant in the world. This summary statement proposes three interrelated aspects to

> the way of gaining knowledge in ritual: It is primarily corporeal rather than cerebral, primarily active rather than contemplative, primarily transformative rather than speculative. (Jennings 1982: 115)

Schilbrack develops Jennings' idea of the ritual knowledge as primarily corporeal by arguing that one can also learn cerebral things, such as "descriptive beliefs" (Schilbrack 2004: 136). In other words, ritual can teach participants not only to *act* differently but also to *see* differently—ritual can teach metaphysics.

Here I use the term "metaphysics" as referring to the general understanding of the nature of reality, much like philosopher Frederick Ferré (1996: 1), to whom "[M]etaphysics is nothing more (nor less) than the theory of reality in general." As such, metaphysical views are something that everyone has. Metaphysical thoughts or beliefs do not necessarily form any constant or coherent worldview. Instead, people's metaphysical ideas are often incoherent and at times even contradictory (Bell 2009: 184–185). Even if religious metaphysical thinking may be only momentary, it can be of great importance for a person, and it can make a meaningful contribution for their take on life.

Thus, even when a metaphysical understanding of the world does not lend itself to a complete and holistic "worldview," metaphysical thoughts are potentially significant when a person is creating a narrative of their life, including a narrative of their self-identity (Giddens [1991] 2006). Moreover, it could be argued that behind every action there is always some sort of presupposed metaphysical understanding of reality, even if this is rarely explicitly discussed, and despite the fact that it may be ambiguous. In other words, humans orient themselves and act according to some understanding of reality, however tenuous or momentary that might be. This is what Giddens (1991: 36–37) calls a sense of reality, which is cultivated in seemingly minor day-to-day routines that keep the chaos of ontological insecurity at bay.

Schilbrack notes that by looking at ritual actions from this angle, it is possible to see how religions can successfully transform more abstract teachings into concrete form, thus giving facticity to their ideology. In addition to explicitly religious rituals, secular ones may also teach participants about metaphysics. In these cases, rituals do not really *make* the person become something (i.e., transforming a daughter into a wife), but instead ritual invites the participant to realize or acknowledge that they (already) are something; the goal of the ritual is to have the participant perceive metaphysical truths "in the flesh" (Schilbrack 2004: 130).[49] This can be exactly the case with death and dying. Death is very much a kind of necessary existential condition, which many of us do not feel to be real; it can be difficult to embody the realization

[49] Schilbrack makes a distinction between two kinds of markings that rituals may inscribe the body with. One is an inscription that has marks of *contingent characteristics*, characteristics that permit an alternative, and the other has marks of *necessary characteristics*. Necessary characteristics would be attributes that a person cannot fail to display, being "characteristics that apply to human existence as such and which therefore do not permit of an alternative" (Schilbrack 2004: 131). When ritual inscribes the participant with marks which represent necessary characteristics, it can be seen as an inscription of ritual metaphysics (Schilbrack 2004: 130).

of one's own mortality. Therefore, I propose, some of the rituals around dying actually serve to convey to the dying an understanding of their mortality.

Aesthetics and participatory orientation in the world of the dying

Although hard to locate at first glance, in the course of the fieldwork I started finding rituals and ritualizations which were practiced, initiated, and created by my research participants in order to orient toward the end of life and death. Analyzing these rituals forms the third and last part of the analysis, Part IV of the book, *Personal Rituals and Aesthetics*. This section of my analysis builds on the previous theories relating to space and ritual metaphysics, for instance, but I also utilize a theoretical division of *participatory versus causal orientation* in order to accentuate the difference between these various kinds of rituals in relation to my research participants.

The kinds of personal rituals in which my research participants were involved reflect the so-called participatory model of engaging with the world, contrasted against the causal model reflected in institutional responses to illness and death. The idea about participatory versus causal orientation was initially introduced by anthropologist Lucien Lévy-Bruhl (1923). In reality, these orientations are not exclusive or strictly distinct but complementary and simultaneously available ways of relating with the world shared by all individuals in all cultures. Furthermore, most human actions integrate features from both of these orientations, although one is often more predominant and perhaps more culturally evoked.

Anthropologist Stanley Tambiah (1990) and historian and scholar of religion Wouter Hanegraaff (2003) continued to develop this conceptualization. Hanegraaff (2003: 374–375) writes that instrumental causality[50] is "a spontaneous tendency of the human mind; the tendency to suspect things that happen in the world to be result of material causation, and to explain events in this manner." Participation, in turn, is often associated with aesthetic, religious, mythical, or magical orientations in the world (Tambiah 1990: 106; Luhrmann 2007; Dawes 2014: 301). Anthropologist Tanya Luhrmann explains that in (magical) participation, such as in the prayer practice of the evangelical Christians whom she studied, "one experiences one's mind as participated in by another awareness, and as affecting that other awareness, that the outer world is full of intentional, interactive consciousness" (Luhrmann 2007: 93). For Hanegraaff (2003: 374), a participatory experience of reality is something immediate; it is "irreducible datum of human experience, which neither permits nor requires further explanation but has to be noted simply as a fact." Hanegraaff sees instrumental causality as a way to *explain* reality (i.e., how the world is independent from our experience of it) and participation more as a way to *experience* reality. It could be claimed, however, that participatory experience also involves thinking about the world, as experiencing encompasses processing on multiple levels.

[50] Hangraaff (2003: 375) prefers to talk about "*instrumental* casusality" over "causality" "in order to avoid any confusion, for example with what Lévy-Bruhl would refer to as 'mystical causality', such as invisible spiritual beings or forces believed to cause material events."

Furthermore, instrumental causality can become a mode of living life, not merely thinking about life.

With the help of the notions of instrumental causality and participation, I can clarify the way in which the different kinds of actions and practices around a terminal diagnosis relate to each other and, further, how they relate to the dominant discourse of biomedicine in contemporary society. Instrumental causality is represented by categorizations and a compartmentalization of reality, rules, and the methodology of positive science and discursive mathematico-logical reasoning (Tambiah 1990: 105). The entire medical world is quite naturally located in this sort of orientation, in which instrumental causality, as way to explain reality, has become an ideology. The material accoutrements of biomedicine—techno-medical equipment, sterile environments, and pharmaceuticals—are all manifestations of trust in the causal way of thinking about the world. These biomedical processes create their very own deathscapes, where certain kinds of rituals of care are practiced.

According to Hanegraaff, the victory of causality over participation (or rationality over irrationality, science over magic, and so on) is not what is historically unique. Instead, what is distinctive is the way in which "this particular ideological system has managed […] to establish itself in recent history as the socially dominant symbolic system in western society" (Hanegraaff 2003: 375–376).[51] The significant point which Hanegraaff makes here (and which has been pointed out by others; see Luhrmann 1991) is that a magical (or religious) manner of thinking does not exclude the scientific or rational way of thinking. Even when one is experiencing things via participation—such as believing in supernatural agencies who are participating in the believer's life at the same time that the believer is participating in the divine (see Luhrmann 2007)—there is no reason why the same person could not also rely on a scientific explanation of matters. In contemporary Western society, however, where instrumental causality is the dominant narrative, offering not only a manner of relating to reality but also a manner of living and acting within the world, there is undeniable dissonance between this cultural ideology and the spontaneous tendency of (magical) participation.[52] One way to lessen this dissonance is to practice participation in the form of rituals, by means of which one can establish a separate ritual space for the participatory engagement (Utriainen 2020).

When I set out to do my ethnography, I discovered only scant evidence of explicitly religious or even spiritual rituals. What I did find, though, were various other kinds of participatory practices marked by metaphysical and existential meaning-making. These practices shared a common element: *aesthetics*. When orienting to the world aesthetically rather than religiously,

[51] Hanegraaff adds that it is not for historians to evaluate the truth claims of this ideology (or any ideology, for that matter), as "the ideology of instrumental causality may simply be recognized as the dominant 'narrative' of contemporary western society; and its defenders' claim of a privileged status compared with other narratives must be noted as being itself a part of the narrative" (Hanegraaff 2003: 376).

[52] This dissonance explains the phenomenon of "disenchantment," which, in other words, is "the pressure exerted upon human beings to deny the spontaneous tendency of participation, by accepting the claims of culturally established ideology according to which instrumental causality amounts to a worldview capable in principal of rationally explaining all aspects of reality" (Hanegraaff 2003: 377).

there is no evident epistemological or metaphysical dissonance in regard to the scientific worldview. Yet, the creative space saturated with imagination and elicited by aesthetic experience allows the existence of religious elements but does not require them. In this space, the person is able to participate affectively in the world. Similar aesthetic experiences as what happens via the arts can be achieved by participating in a (mythic) landscape or sacred geography (Tambiah 1990: 106–107). Whereas Tambiah elaborates on various examples of anthropological studies in which nature has a sacred component and a spiritually empowering influence on people (whose identities are magically and relationally structured), the experience of "participation in nature" is relevant even for today's urban Finns, as we shall see.

The imagination and the potentiality that are present in both aesthetics and ritual can be seen as a kind of virtuality. This is how anthropologist Bruce Kapferer has interpreted ritual, as a *site for virtuality*, and this view complements the theory of rituals as participatory modes of action (Kapferer 2004, 2006). According to Kapferer, in the virtuality of the ritual, the ritual participants are able *to enhance their potentialities, invite change upon themselves, or practice new solutions and change*. This perspective helps to elucidate the motives for the personal rituals in which my research participants engaged, as well as why those rituals were so meaningful for them.

The word 'virtual' refers simultaneously to something fictional and illusory and to something with the potential capacity to enhance reality. Various forms of art, (religious) ritual, and environmental aesthetics (as in a landscape or even a single element of nature) are experiences which enable a creation of virtual space for learning, absorbing, tolerating, and even celebrating the tensions and paradoxes of life. In this kind of virtual space—whether artistic, ritual, or environmental—things otherwise impossible become possible; through a ritual frame we enter the virtual "as if" world of possibilities (Utriainen 2016, 2020).

I have called this sort of participatory engagement *aesthetic experience*, since aesthetics reflects the one common element in experiences of art, ritual, and landscape or nature (Butters 2016). Here participation is not just a way of experiencing and sensing reality. It becomes a way to reorient oneself by facilitating new, relevant, and metaphysically meaningful understandings of one's personal life situation. Subsequently, aesthetic experience is not only sensory but also cognitive; it can shape one's (metaphysical) understanding of the world. Such participatory engagement is an example of the kind of relational processual manner of living and dying that I wish to illuminate in this study.

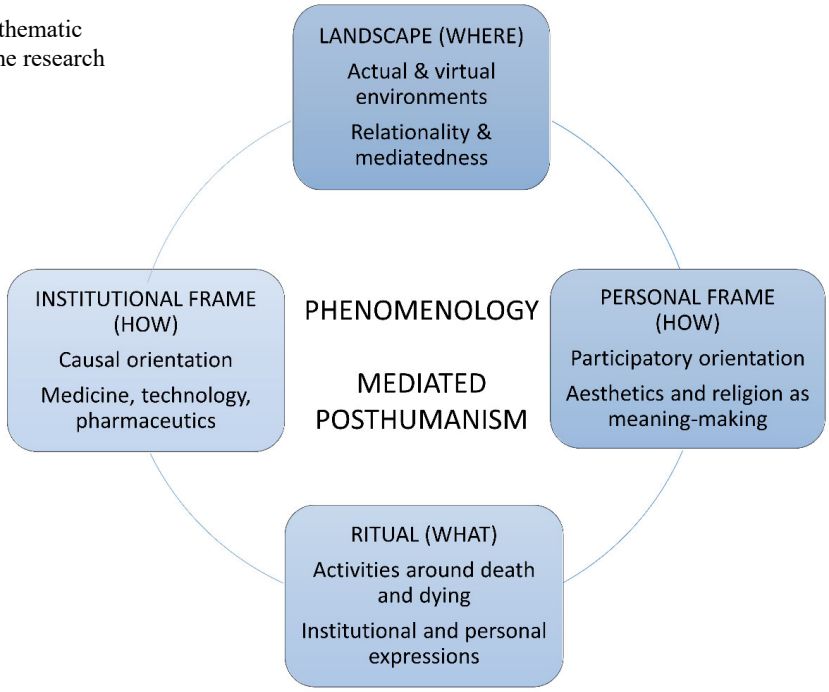
2.4 Visuals of the theoretical thinking of this work

Since I draw from many different theoretical sources, I have created a set of diagrams intended to clarify the theoretical constellation of my work and how it relates to the various aspects of the analysis (see Figures 2, 3, and 4). As seen in Figure 2 above, the overall theoretical approach arises from phenomenology and critical mediated posthumanism; whereas the former looks at

various intersubjectivities from the embodied phenomenological perspective, the latter offers a contemporary perspective, emphasizing relationalities (including non-human actors).

The overarching research topic can be approached with questions of *what* happens around the dying people, *where* it happens, and *how* it happens.[53] This approach is represented in Figure 3. Under "landscape" are the themes related to (actual and virtual) environments, as well as relationality and mediatedness. Correspondingly, under the section for "ritual," there are the various activities which the dying patients do themselves, or which are done to them by others—thereby including both personal, social, and institutional expressions. Finally, the question of how is divided into two sections, that of the "institutional" and that of the "personal frame" of action, in which different orientations—causal and participatory—are applied. Again, it is important to note that these frames of institutional and personal tend to merge and become intertwined to some extent, since medicine can become a personal ritual and, for instance, existential meaning-making can be also applied to medicine. However, this diagram serves to illustrate the main thematic approaches I take toward my research material.

Figure 3. Main thematic approaches to the research material.



By adding more theory in relation to body and space in the diagram (see the green circles in Figure 4), it is possible to visualize how the various theoretical angles fit together with the different themes and the whole of the study. Generally speaking, my research topic is very subjective, personal, and even intimate, yet since the personal end-of-life experiences are

[53] This "what," "where," and "how" approach, developed during the research process, was presented at an international Death Studies conference in Bath in 2019 (DDD14).

strongly embedded in institutional care (practices and places), the research touches upon institutional and sociopolitical aspects as well. For this reason, I deploy seemingly very different kinds of approaches in the research material: the overall approach of phenomenology is strengthened by anthropological theories of ritual. This kind of a "tandem approach" ensures me with tools to analyze the deeply subjective experience within its societal context (Desjarlais & Throop 2011: 95). For instance, the matter of space can be viewed from a socially produced angle and from the phenomenological angle of lived space. The Deleuzoguattarian striated can be associated with institutional (structuring) aspects of space and practice and the smooth can be associated with lived personal space and practice; however, as previously mentioned, these categories are never completely separate but in a dynamic relationship with each other. As we shall see, smoothings can happen equally in the institutional frame and striated can manifest via personal rituals, which structure space and time, for instance. In regard to analysis of the multiple body in various kinds of rituals, we can differentiate between the Foucauldian disciplined body, which may become objectified within the institutional practices (and thus be under Spinozian *potestas*), and the extended and virtual body empowered by *potentia*.

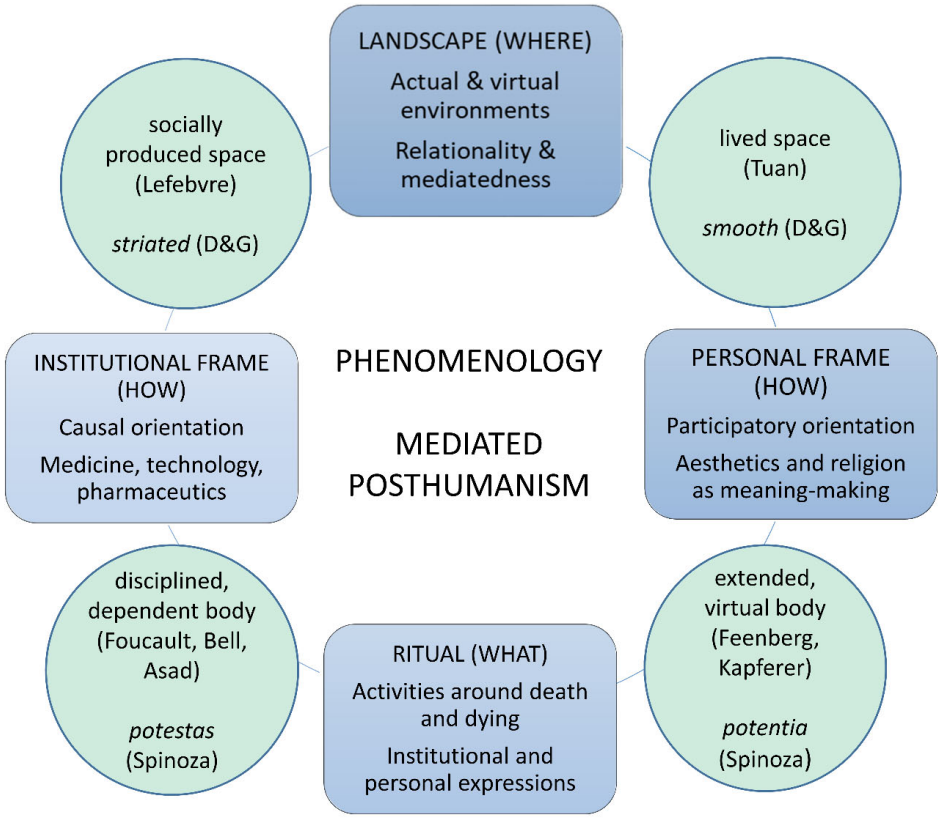


Figure 4. The main approaches to the topic of the study with the applied theories.

3. CONTEXT, METHODOLOGY, AND RESEARCH ETHICS

3.1 Context

General context for the study

Especially in the fields of medical anthropology and social studies regarding health and illnesses, the proper contextualization of a research is of major importance. In their article on methodology in health research, Canadian psychiatrist Marghalara Rashid points out that careful contextualization helps to prevent misrepresentation of participants' meanings and purposes (Rashid et al. 2015). Even though the immediate location of the fieldwork sites are not specified (for the sake of personal data protection), there are other ways to contextualize the study, such as underlying national health policies and practices that influence the ground-level realities. Moreover, the contextualization is also in line with the very important basic observation that the research participants (dying people) so clearly identified themselves as *patients*.

The meaning of the context for my research participants became evident to me after I started the fieldwork. Rather than talking about the terminal condition *per se*, most of the conversations surrounded general issues of being *ill*. Patients talked about their illness trajectories and their attempts to create a sense of their whole experience of being ill. I gathered a few possible reasons for patients wanting to talk about being ill so much, rather than anything related to dying. First, even when a patient had been referred to palliative care or to hospice, it was sometimes difficult for them to accept the finality of the situation. Indeed, quite many were still seeking or hoping for a cure, or at least some life-prolonging treatments and solutions. In other words, their lived reality was defined more by being ill than by dying. Second, the kind of experiences the patients had had during their whole illness trajectory—which varied time wise from a few months to several years—affected the way they experienced their situation at the moment of the research. Just as life experiences in general shape people and affect their ability to handle difficulties, the research participants' previous experiences with medical encounters affected how able they were to interpret their contemporary situation. This does not mean that patients did not assert their authority and their own agency in certain situations, but rather that during a moment of vulnerability (when one fell ill, for instance), one could easily become much more dependent on the environment. Consequently, the significance of the surrounding world (e.g., people, places, practices) became pronounced. For this reason, I found it important to try to understand the way in which people ended up in certain situations and had certain kinds of encounters and experiences with the medical world.

Contextualization can happen on various levels. On the cultural and historic macro level, Finland has a rich death culture with a vast body of folklore and various spiritual practices and rituals. While most of these practices belong to history by now, some aspects of the ancient

death culture can be still found in Finnish art (music and the fine arts, for example).[54] Some references to the old, death-related vernacular folk beliefs and imagery seem to exist even today; for instance, my research participants talked about experiences of *sielulintu*, the "soul bird" (see Chapter 10). Otherwise, as explained in the first chapter, Finland is a rather secular Northern European country with a majority of people belonging to the Lutheran church (73% in 2015).[55] The most noteworthy features of "Finnish Lutheranism" are related to the societal ideal of seeking the common good, trust toward and responsibility of one and other, meaningfulness of work ("work as a vocation"), and the importance of equality in the society (Ketola et al. 2018: 23–31).[56] In general, religious sentiments are considered to be private; in regard to religious behavior, Finns could be described as rather passive (Taira 2012: 23; Taira 2015). Attendance at church ceremonies, for example, is very low—mostly people go to church for rites of passage (weddings, funerals, baptisms) and calendar rites such as Christmas. Hence, the phrase "belonging without practicing" describes most Finns well (Taira 2012: 23).

While the cultural and religious background is part of the macro context, another very important element is the healthcare system in Finland. The Finnish healthcare system is largely publicly funded, which grants everybody the access to healthcare services.[57] However, researchers in the field of social and healthcare politics agree that an increasing number of neoliberal elements (e.g., the marketization and privatization of healthcare services, augmenting individual responsibility in regard to one's wellbeing, converting patients into customers) is taking over Finnish socio-political discourse and decision-making (Hoppania 2019; Harjunen 2017; Jokinen 2017; Rokkonen & Lehto 2017). Although the political changes in Finland may have been more moderate or slower than in other European countries (see Julkunen 2017), the political discourse and atmosphere in regard to healthcare have changed in Finland since the 1990s, and especially since 2015 (Hellman et al. 2017).

[54] The theme of *Tuonen joutsen*, the "swan of death," for example, has featured in the work of numerous celebrated Finnish artists, such as Jean Sibelius, Akseli Gallen-Kallela, and Eino Leino.

[55] This reflects roughly the time of the fieldwork. The decline in Church membership is notable, however. In 2019, only 68.6% of all Finns belonged to the Church (https://fi.wikipedia.org/wiki/Suomen_evankelis-luterilainen_kirkko#Kirkon_j%C3%A4senet). In Helsinki, the membership percentages are even lower: in 2018, only 53% of the inhabitants were members of the Lutheran Church (https://www.hs.fi/kaupunki/art-2000006076021.html).

[56] Trust in others is implicit also in Finns' trust in various national institutions; according to a Gallup poll conducted in 2019, over 70% of Finns trust the healthcare system either a "fair amount" or a "great deal" (Lääkäriliitto 2019b).

[57] For instance, in 2020, one chemo- or radiation therapy session costs around €10 and a night in the hospital is approximately €20 (https://stm.fi/terveydenhuollon-maksut).

This perspective does not dominate my analysis, yet I wish to keep it in mind, as it may affect the discourse and practices in the field (Hoppania 2019). On one hand, this refers to the general frame of the care of the dying, which mostly takes place within healthcare settings. On the other hand, since the efficiency orientation accentuated in neoliberal policy-making penetrates the whole society (Eskelinen et al. 2017), it also affects how frailty, illness, and inefficiency are understood and experienced. How this kind of atmosphere influences people's illness experiences and how it relates, for instance, to the fear of being a burden to one's family (which came up a few times during my research) are relevant questions to pose, even though it was not in the scope of this study to find the answers to them. The following graphic representation (Figure 5) depicts the various affective contexts in which the patients' experiences are embedded.

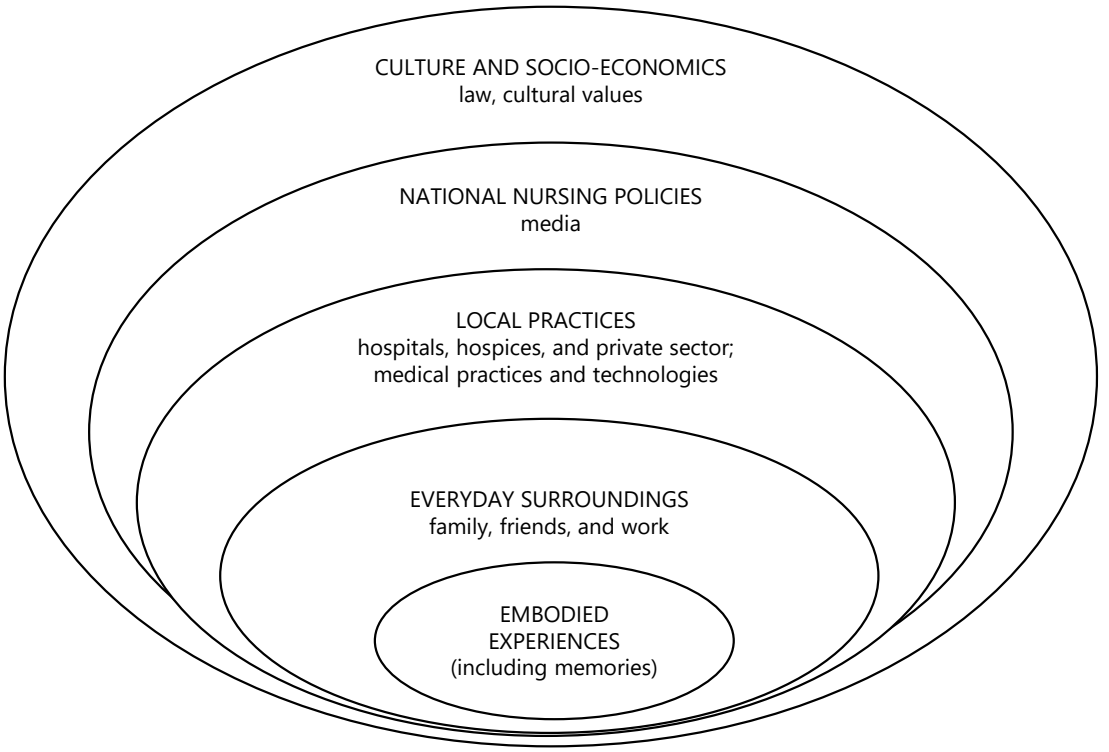


Figure 5. The micro, meso, and macro contexts which affect patients' experiences.

Since I seek to understand the patient's lived experiences, my analysis happens on the micro level. However, because the individual's experiences are born in relation to, and in dependence on, the meso and macro levels of society, I will make some references to those other contextual levels throughout the study. As I try to make sense of how these elements intertwine with the situated perception and embodied understandings of patients, phenomenological approach

helps "to consider the ways in which political, social, economic, and discursive formations intersect with the operations and felt immediacies of bodies in a number of sociocultural settings" (Desjarlais & Throop 2011: 90).

Palliative care strategy in Finland

The national healthcare policies in Finland, such as the Current Care Guidelines (*Käypähoitosuositus*) and local practicalities and practices of various physical care settings, directly influence the way in which healthcare, including palliative care, is organized, and hence they also affect the way in which people access and experience their care.

In Finland, there are four general care strategies (see Figure 6), which refer to the primary goals and aims of care in relation to cancer treatments (which was the common denominator among my research participants):

The four-staged model for care strategies[58]

Care strategy	Primary objectives of care
Curative treatment	Full recovery
Disease-modifying (life-prolonging) treatments	Control the progression of the non-curable primary disease and prolong the life span
Palliative care (ICD-10 code Z51.5)	Alleviate suffering and foster quality of life when the course of the disease can no longer be affected
End-of-life care (ICD-10 code Z51.5)	Palliative care close to imminent death (days or weeks), involving care of the dying

Figure 6. The four-staged model of care strategies. Current Care Guidelines 2019. Good palliative care is included in all of the care strategies (Saarto 2015).

In recent years, there has been much discussion about the early and gradual integration of palliative care with the care of life-threatening illnesses (Kaasa et al. 2018; Gomez-Batiste 2019);[59] one reason for this is the increasing number of patients with chronic metastatic cancer. This trend is also visible in the Finnish recommendations, which suggest that palliative care ought to be offered in combination with the different care strategies (Current Care Guidelines 2019). In practice, this means that the simple dichotomized division of care into curative versus

[58] This model is also found online: https://www.terveyskyla.fi/palliatiivinentalo/palliatiivinen-hoito/hoitolinjat.
[59] Internationally, Kaasa et al. (2018: e591) have proposed a three-fold distinction: curative, life-prolonging, and palliative care; at the same time, they emphasize the integration of palliative care with the care of more advanced diseases.

non-curative does not necessarily correspond to the realities of patients, especially not those whose metastatic cancer has become chronic and who live for years with their condition. The imbricated relationship between the curative, disease-modifying, palliative, and hospice care strategies can be depicted in the following manner (Figure 7):

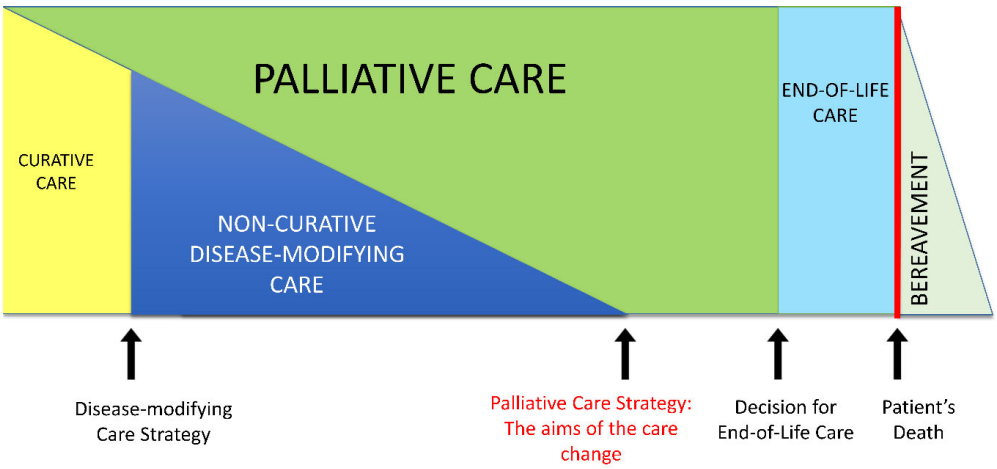


Figure 7. Palliative care model for cancer patients. Original diagram by Tiina Saarto (2015).

However, as professor of oncology and palliative medicine Stein Kaasa notes, for many patients and professionals alike, curative care and palliative care continue to represent two different cultures and paradigms with differing goals of care (Kaasa et al. 2018).[60] In the case of cancer, this is sometimes summarized as "tumor-centered" versus "patient-centered" care (see Kaasa et al. 2018: e588–e592).[61]

[60] The dichotomous perception of palliative/hospice care and curative care is based on the historic roots of palliative care. The hospice movement started to develop in the UK and the USA in the 1960s, largely as a counter-reaction to the medicalization of death (Lewis [2006] 2011: 6). The principles of hospice philosophy developed by Saunders quickly spread around Anglo-Saxon countries. Concurrently there appeared other critical studies and publications claiming that death had become taboo in modern society and that care of the dying was neglected (e.g., Hinton 1964; Glaser & Strauss 1965; Gorer 1965; Kübler-Ross [1969] 2009; Becker 1973; Ariès 1974). Thus, the moment was propitious for a larger hospice movement. If hospice was first developed outside of the main healthcare systems, within a few decades it became a part of mainstream medicine in the form of palliative care and palliative medicine. This mainstream move over the years has not happened without critiques, however. At the academic conferences on death and dying that I have attended in the past five years, social scientists and nursing professionals from different parts of the world have criticized that contemporary palliative care has become too medicalized and gone astray from its original ideals set out by Saunders (see also Randall & Downie 2006). This opinion was also expressed by some of the professionals I encountered during the fieldwork.

[61] I could hear echoes of this kind of understanding among the people with whom I did my fieldwork; I will return to this later on.

Treatments and care in advanced cancer

In the case of cancer (which all of my research participants had), the single-most important factor in the diagnosis is whether the disease is local or advanced with metastasis.[62] In the case of a local tumor, curative care follows; this aims to destroy all cancerous cells, ideally ending with full recovery of the patient. There are nowadays a variety of treatment options. In addition to the traditional therapies such as surgery, chemotherapy, and radiation, there are treatments in immunotherapy, targeted therapy, hormone therapy, stem cell transplants, and genetic precision medicine. All these are often used alongside the more traditional therapies (such as chemo). Due to the continuous advancement of cancer research, the discovery of new drugs and treatment options has improved general cancer prognoses significantly. Regularly making headlines in the media, new medical innovations are a source of much hope for many people. At times, however, the sensationalized news of medical breakthroughs create false hope and misunderstandings for patients (Janes 2006).

If cancer has spread widely throughout the body, it becomes much harder to control. Metastatic cancer is treated with disease-modifying treatments or, in more advanced cases, palliatively.[63] Non-curative disease-modifying treatment "constitutes an interdisciplinary treatment effort for patients whose disease is unresponsive to approaches with curative intent and involves life-prolonging treatment and palliative care" (Mroueh et al. 2019). Once the attending doctor assesses that it is time to make the shift from the curative care strategy to disease-modifying care and early integrated palliative care, the protocol is to initiate discussion about this with the patient and possible family members (see Figure 7; Lehto 2015).[64] This is also the time (at the latest) when the Advance Care Planning (ACP) ought to be made by the physician in collaboration with the patient.

ACP is a document that includes various kinds of information relating to end-of-life care, such as the record of the care strategy (aims of the care), the treatment plan and medication, possible restrictions of the care (such as a do-not-resuscitate order, or DNR), the patient's wishes in regard to their end-of-life care, and the plan for the care location at the time of death (Current Care Guidelines 2019).[65] When the decision is made to engage in palliative care, it

[62] Some research participants also had other illnesses.

[63] The contemporary care policies emphasize the presence of palliative care in all of the care strategies (Saarto 2015).

[64] Among other prognostic tools, in order to estimate if it is time for the patient to be referred to specialized palliative care, the so-called "surprise question" is sometimes asked: "Would you be surprised if this patient dies within the next 6–12 months?" In the case of a negative answer, palliative care should be applied (Kaasa et al. 2018: e608).

[65] According to the Finnish law on patient's rights (1992/785: 6§), a patient can refuse medical treatments (see https://www.valvira.fi/terveydenhuolto/potilaan-asema-ja-oikeudet-oikeudet/potilaan-itsemaaraamisoikeus). In regard to restricting care, the doctor is ultimately responsible for making the decision about what is correct and timely.

ought to be documented in the patient's records (with ICD10-code Z51.5 – Palliative care).[66] The decision for end-of-life care happens when death is foreseen within the next weeks or days, and it contains a promise to organize symptomatic care for the dying and the necessary support for them, as well as for family members, during the last weeks of life and after death. The end-of-life decision always includes a DNR decision; the decision to shift to hospice care also needs to be documented in the patient's records (Lehto 2015; Saarto 2017: 7–8; Lehto et al. 2019).

In regard to my research participants, all of them received some medical treatment after their diagnosis (which was not always non-curative at first). After the curative treatment failed, or after the relapse of the disease, the disease-modifying treatment could still benefit from various types of chemo, radiation, and hormone therapy. In palliative care, however, the overall aim is to treat symptoms and alleviate pain (in regard to which radiation therapy is one possible treatment). At this time, it becomes important to carefully discuss the pros and cons of the treatment, especially in the case of those therapies which oncology refers to as "aggressive," such as operations or chemotherapy (Hietanen 2016; Tarkkanen et al. 2020). Many professionals find these encounters challenging, and sometimes the shared decision-making over these matters becomes complex due to communication difficulties and differing expectations between the doctor and the patient (Galushko et al. 2012; Tarkkanen et al. 2020). Assigning a patient a correct care strategy, including ending potentially harmful treatments, is often a challenge for caregivers (Hietanen 2015a, 2016; Tarkkanen et al. 2020).[67] International and Finnish research literature has shown that that despite recommendations, aggressive cancer treatments still tend to be used too widely at the end of life (Rautakorpi, Mäkelä et al. 2017; Rautakorpi, Seyednasrollah et al. 2017; Hirvonen et al. 2019).[68] Aggressive treatments toward the very end of life may deteriorate life quality; furthermore, they increase hospital deaths significantly.[69] Their use also contrasts with Finland's national recommendations, according to

[66] The dynamic change that has happened in Finland in regard to palliative care is visible in the frequency of usage of ICD-code Z51 in patients' records at Tampere University Hospital, where they increased from under 100 in 2013 to almost 1000 in 2017 (Lehto et al. 2019).

[67] Communication between doctors and patients in general has progressed a lot since the 1980s, when it was common to not even tell the patient that they were actually dying (Seale 1998: 108). However, it continues to be a challenging moment for a doctor to share their prognosis assessment with patients, and some still seek to avoid it (Lamont & Christakis 2001; Fenton et al. 2018).

[68] According to a recent Finnish study, "20% of the patients received systemic cancer treatment during the last month of life. This was in line with another Finnish study where 18% of the patients received IV chemotherapy during the last month. The corresponding figures during the last two weeks of life were 18% in this study and 7% in the study by Rautakorpi et al. However, in the present study orally given chemotherapy and biological treatments were also included, which could explain the higher rate of patients receiving systemic treatment at the EOL" (Hirvonen et al. 2019: 5). Furthermore, "In the present study, 29% of the patients received radiotherapy during the last month of life and 14% in the last two weeks, respectively. The prevalence of radiotherapy in the present study is somewhat higher than in the previous studies. In another Finnish study from 2005 to 2013, the corresponding figures were 23% and 12%, respectively" (Hirvonen et al. 2019: 5).

[69] Recent Finnish studies (Rautakorpi, Mäkelä et al. 2017; Rautakorpi, Seyednasrollah et al. 2017) have shown that of those receiving chemo or radiation therapy during the last weeks of their life, 40% die in specialized medical care.

which cancer patients should be provided with the possibility to die in hospice care, whether at home or with proper facilities in general healthcare (Saarto 2017). As Hirvonen et al. note:

> The lack of a PC [palliative care] decision or postponing it to the last month of life reflected a significantly increased risk for aggressive cancer treatments during the EOL and delayed the access to PC services. Early-integrated PC should be offered more systematically to ensure timely advanced care planning and access to palliative and EOL care. (Hirvonen et al. 2019: 6)

Thus, the early integration of palliative care protects patients from potentially futile diagnostics or treatments at the end of life, when holistic care for the dying and the family members could instead be provided.[70] Care strategies are not merely words on paper. When applied in practice, they very concretely guide the kind of medical, psycho-social, and existential care that is offered to the patient, and in this way they play an active part in forming the patient's experience of their illness and end of life.

3.2 Qualitative research method: Ethnography of palliative patients

Planning the study and seeking the ethical approval

The fact that there is relatively little qualitative and ethnographic data on how terminally ill patients perceive, feel, and think about their situation assured me of the importance of doing fieldwork among dying people. Despite the possible emotional challenges that it could bring, the ethnographic research approach was needed to elicit the kind of information and perspective that I was seeking to apprehend: namely, the embodied experiences of the patients themselves (see also Reeves et al. 2008). Furthermore, since I have a background in anthropology and previous experience in ethnography, the idea of this method was conceivable. In anthropological ethnography, the researcher deals constantly with questions of being at the same time an insider and an outsider. An anthropologist's task is to learn the insider's emic knowledge and then to relate that to the etic knowledge of academic discourse.[71] Anthropological training equips the researcher with analytical lenses that have the capacity to perceive ordinary everyday phenomena as something extraordinary. While studying cultures other than one's own, an anthropologist develops a sensibility to regard one's own culture as something wondrous; previously unquestioned manners of thinking and acting provoke questions and become worth studying. As a result, it is common for anthropologists to query cultural categories which may normally be taken for granted (Van Dongen & Fainzang 1998; Campbell 2011).

[70] In the education on palliative medicine, clear emphasis is put on the importance of Advance Care Planning (ACP) for every patient, including a proper care strategy designed early on (Saarto 2017: 7–8; Lehto et al. 2019). This may also prevent some of the contested situations in which the patients and their families can find themselves.
[71] There are contemporary academic discourses, such as those related to the "ontological turn," within the fields of anthropology and the study of religion in which this rather traditional emic-etic perspective has been strongly debated (see Carrithers et al. 2010; Laack 2020).

When I first presented the idea for my research at a postgraduate seminar in the Study of Religions (in the Department of World Cultures) at the University of Helsinki, many found it compelling. But there were some doubts also. For example, a colleague wondered whether anyone in such a situation would want to talk to a stranger. This was a valid question, although later it proved not to be a problem at all (Hutchinson et al. 1994; Lawton 2001). As discussed in our seminar, it was obvious that my study entailed additional ethical questions, which would require serious attention and very detailed planning.

Because I wanted to explore a range of experiences, I thought of recruiting patients from different locations (e.g., hospitals, hospices). In order to conduct any research in hospital premises, the research plan has to be approved by the university hospital's ethical board.[72] For the application to the medical ethical board I also needed a supervisor at the hospital. I was fortunate in this regard that professor of palliative medicine Tiina Saarto agreed to supervise my study. The process of the ethical approval was complex, since the research plan, along with all the other forms, needed to be written in terms of medical research, according to the guidelines and criteria created for medical studies.[73] The first application did not go through; among other things more clarifications were needed to explain the legal protection of the staff members. Since this issue proved to be complicated, I decided in my ethnography to reduce to a minimum the focus on staff. After filing a new application with the required clarifications, I received approval from the ethical board. The research permissions were then sought from the oncology ward at the university hospital. The hospice home had already given conditional permission (pending the ethical board's approval), and so therefore I was then ready to proceed to the field.

Ethnographic research methods

Ethnography is a classical methodological orientation in anthropology and other social sciences, which sociologist Martyn Hammersley (2006: 6) defines as "a form of social […] research that emphasizes the importance of studying *at first hand* what people do and say in particular contexts." In anthropology, this has traditionally meant rather lengthy (at least a year) fieldwork among the community under the study, often far from one's home.[74] Fieldwork commonly involves participant observation and relatively open-ended interviews designed to understand people's experiences and perspectives, and it may be complemented by the study of various sorts of official or personal documents (Hammersley 2006). In participant observation,

[72] An evaluation from the medical ethical board is required even if the research site is not part of the university hospital, but any other medical setting (such as a private clinic, for instance).
[73] The position of research in the social sciences and humanities in regard to medicine and hospital institutions is an important topic that requires more discussion (Koenig, Back & LaVera 2003; Gysels, Evans & Higginson 2012; Lämsä 2008, 2016).
[74] Anthropological fieldwork has changed greatly over the last thirty years. There has been strong debate during recent years about ethnographic methodology itself, especially since ethnographic methods have been embraced in various other disciplines (see Hockey & Forsey 2012; Ingold 2014).

the researcher seeks to depict and explain people's actions within their own environment, as well as people's interpretations and understanding of their actions and environment. Research subjects [75] are approached holistically, which means that people are always studied as contextually (culturally) and historically situated. Ideally the researcher collects data by being physically present in the living environment of the research subjects; by participating actively in their quotidian life, they can carefully observe the object of research. By its nature, ethnographic research mostly applies the hermeneutic interest of knowledge; the purpose is to learn how the world is experienced and perceived by the research participants (Hastrup 1995; Hammerley & Atkinson 2007). Ethnography as a research approach is especially suitable for studies within the realm of phenomenological anthropology that seek to capture the subjective embodied understandings of research participants.

Since the research material is born in the interactive relationship between the researcher and the researched, there is neither a need nor epistemological basis to render the researcher invisible in the research process (Hockey 1990: 198–199; Hastrup 1995: 45–47; Visser 2017). Actually, it is the other way around. For the sake of the validity of the research, the researcher's positioning should be made explicitly open and reflexive; only in this way can there be a critical evaluation of the research process and the acquired data. Inspired largely by phenomenology (Heidegger [1927] 1962; Husserl [1936] 1954; Merleau-Ponty [1945] 2005), the intersubjective nature of knowledge formation is today an essential notion in many intellectual conversations within anthropology (Csordas 1994, 2011; Jackson 1996; Knibbe & Versteeg 2008). Furthermore, when studying illness and dying, one studies life experiences which are fundamentally shared by all humans; they are also shared by every anthropologist or social scientist studying these themes. Like the renowned death scholar Douglas Davies has remarked, "We are all participants in mortality, not just observers" (see Woodthorpe 2011). This commonality is challenged by the difference that the researched is the one in the position of an actually dying person; they become the other, living their end of life, whereas for the researcher death remains personally remote.

The shared nature of experiences brings the researcher closer to the researched; regardless of all the various cultural differences the researcher may have with the researched, this shared human commonality serves as a foundation for mutual understanding (Hastrup 1995: 57). Given the especially emotionally charged nature of death research, however, this commonality can cause complications, which each researcher needs to encounter and solve in their own manner (Hockey 2007; Woodthorpe 2011; Borgstrom & Ellis 2017; Visser 2017). The way in which these reflections comprise part of the final research report can vary greatly (Davies 2010: 9–14). In my case, I will bring forward both my own position and my personal experiences

[75] What is called the "research object" in quantitative research traditions is usually depicted as a "research subject" or "research participant" in anthropology. This has to do with the epistemological emphasis. In anthropology, knowledge formation is interpreted to happen in a sort of collaboration together with the research participants. The amount of theoretical conceptualization that the researcher then does by herself varies from study to study.

(especially with my mother), which I believe are essential in the process of knowledge formation—and thus also the creation of this study.

Since the methodology was cultivated within anthropology (and in Finland notably also in the field of study of religion; see Anttonen 2010), ethnographic methods have become popular in various disciplines in the social sciences, but also in education and health research (Rashid et al. 2015). Simultaneously, the methods themselves have been modified to suit these new contexts of study. Compared to a "traditional" anthropologist who would immerse in the research site for a year or two, social ethnographers tend to do much shorter periods in the field. For instance, they may spend a few hours per day and a day or two per week in their particular locale of interest. This describes well the kind of fieldwork I engaged in myself. In this type of fragmented "part-time fieldwork," the process of material collection is somewhat different. This has caused some concerns about the adequacy and the validity of the methods used (Hammersley 2006; Ingold 2014), as this kind of fieldwork automatically produces more segmented ethnographic knowledge, in which the effects of the larger cultural background may not always surface as well as through a more immersive and longer time in the field. Furthermore, when the whole fieldwork period is shortened to last months rather than years, there is a threat that the perspective may become ahistorical (Hammersley 2006). All of this is quite contrary to the anthropological ethnographic project, which can be described as having "long-term and open-ended commitment, generous attentiveness, relational depth, and sensitivity to context" (Ingold 2014: 384).

Since my fieldwork took place over several years, I am not particularly concerned about the question of ahistoricity. Furthermore, on a personal level, I have sought to create an understanding of the research participants' situations by including their reflections on past experiences which had affected them. On a more societal level, my being involved in various manners in the field of palliative care and hospice enhanced my understanding of the dynamic aspect of the field. By addressing the sociohistorical context in which the study is made, one can minimize the inevitable problem of ahistoricity; after all, however carefully one may try to contextualize and historicize, an ethnography is always a momentary and situated process of capturing a certain social reality.

In the classical anthropological model, the period of actual immersive fieldwork is followed by a so-called distancing period, when the researcher withdraws from the field and starts working with and analyzing the research material. If the fieldwork is done in a "part-time" manner, the subsequent distancing phase is different. This can complicate the distancing process, which often is thought to be both emotionally and intellectually crucial for the researcher. Of course, in some areas of research (especially in regard to study of dying), complete distancing may be unrealistic (Woodthorpe 2011; Visser 2017). Furthermore, in the contemporary digital era of massive globalization, it can be questioned if this sort of clear-cut separation from "the field" (wherever it may be) and "the Academy" can be still maintained.

At least intellectually and emotionally, if not physically and concretely, the researcher is continuously moving between the field (research material) and the Academy (theoretical thinking) (Hastrup 1995: 49–60). This also depicts my way of doing research, for it is essentially what creates anthropological knowledge (Hastrup 1995: 49–60), and eventually it leads to the writing of the actual research report.

Participant observation and ethnographic interviews

During the course of the fieldwork, my understanding of the research topic became more nuanced. In order to find answers to my research questions, I needed to pay attention not only to things that were said and expressed but also to things that remained unexpressed. Furthermore, while I was specifically interested in the experiences of the patients, I realized that in order to fully fathom them I had to also comprehend the environments in which they were engendered. In this way, over the course of the fieldwork some facets of my research problem became more salient than others.

I practiced participant observation throughout my fieldwork in various settings. Following the ethical approval, I included only minimal research observations on practices initiated by nursing and medical staff; I did not observe physical medical treatments at all. Instead, my observations in the medical surroundings were limited to some very general remarks on activities, without any specification in regard to the staff, and I deliberately focused my attention on the patient, the space, and especially the patient's relationship with their surroundings.

In the hospice context, I occasionally worked in a similar role as the volunteers of the hospice. I engaged in care of the patients, not just my research participants but anyone needing assistance. Thus, I was actually participating in the daily life on the hospice ward, and by being involved in the everyday activities I learned a lot. In general, the relationality of the medical surroundings, including the staff, came up in a significant way in the narratives of the research patients; my material thus contains descriptions of the relations between the patients and the staff, as narrated by the research participants.

Interviewing was the other major method of collecting information and seeking to gain an understanding of the people researched. I did not, however, pursue the interviews right at the beginning of meeting a new research participant; I even hesitated to use the word 'interview' (Finnish: *haastattelu*), since it could connote a structured conversation or even a closed questionnaire, which I was not conducting. Furthermore, due to the sensitive research topic and the fact that my research participants were vulnerable, a slow and considered manner of getting to know people was essential in forming a relationship. Yet, this was not the only reason why I

did not want to pursue a heavy interview right at the beginning.[76] After getting to know people better, I felt that they talked to me more about what they really thought instead of saying things that they perhaps assumed that I wanted to hear.[77] Time wise, therefore, most of my fieldwork consisted of "just hanging out" with the research participants, chatting and casually conversing with them. There were also the moments when we had an attentive conversation, and sometimes I conducted a semi-structured interview with the participants.

Using interviews as a primary source of data has been critiqued in the social sciences, and it would be indeed naïve to assume that interviews offer some sort of "authentic" or "truthful" representation of the interviewee and their reality (Skinner 2012). Narration is always based on an interpretation and a chosen version of the past; in actuality, things can happen simultaneously whereas when they become narrated they appear in a diachronic manner and people apply causes and conditions that may not have been there. In addition to the fact that the interviewee may have a number of personal and social reasons to tell their story in a particular manner, the researcher makes selections from interviews, and only certain narrations become analyzed and included in the research report. The critical perspective on interviews as a research method notes the way in which our contemporary society is an "interview society" (Atkinson & Silverman 1997, cited in Skinner 2012: 11). The general public is saturated with interviews on television, the internet, newspapers, and so on, and they know how to perform in an interview (Skinner 2012: 10–12). This becomes especially problematic if the researcher uses interview responses uncritically, simply repeating them as the "results." As anthropologist Jonathan Skinner puts it: "We might say, then, that in the interview society, the interview narratives sound good, feel good and look good for the interviewer and the interviewee. But this is a rehearsed self up for analysis. This is research by repetition rather than insight" (Skinner 2012: 12).

Instead of taking narratives as accurate depictions of reality *per se*, sociologists Jaber Gubrium and James Holstein consider interviews to be "reality-constructing, meaning-making occasions" (Holstein & Gubrium 1995: 4). They see the interview as "an active encounter," and they emphasize that "researchers should consider the *hows* of the social process in the interview setting as well as the *whats* of the lived experience in the interview content in their interview work" (Holstein & Gubrium 1995: 5). This approach comes close to that of the ethnographic

[76] Sometimes I had no option, however. For instance, in the case of the research patient Matti, I met him only once and we talked once on the phone. He died soon thereafter. Because of his professional background, he was familiar with issues of death and dying, and he invited me to seriously engage the issue.

[77] For instance, in the very beginning of my fieldwork, I was visiting the day hospice group for the first time and I introduced myself and my study, saying something like "My name is Maija Butters, and I come from the University of Helsinki where I am conducting PhD research in the field of study of religion…" On that first day, I heard the word 'church' mentioned more than any other day during my fieldwork. Later I realized that this must have been because I had introduced myself as a *scholar of religion*; people had assumed that it was religion I wished to hear about, and they were seeking to perform accordingly. After this, I avoided talking about the study of religion. Instead, I usually said that I was doing a cultural study on seriously ill people and hospice (see also Day 2013). When in the field, I also rarely defined my research participants as "terminally ill," since not all thought of themselves as such.

interview, which is a methodologically specific process that includes critical and theoretical analysis of both the content of the narration and the actual interview situation. Anthropologists Jenny Hockey and Martin Forsey write that ethnographic interviews

> "commit the researcher to understanding the lived experience of the participant/interlocutor by asking about and listening closely to the beliefs, the values, the material conditions and structural forces that underwrite the socially patterned behaviours of all human beings, along with the meanings people attach to these conditions and forces." (Hockey & Forsey 2012: 83)

The ethnographer seeks to not only get answers to certain questions but also tries to develop an understanding of the various material and immaterial factors shaping and affecting what is told and how it is told. Narrations involve stories about lived experiences, which an ethnographer emphatically seeks to apprehend. The actual moment of the interview always deserves to be analyzed on its own terms as an active encounter, in which the reality is re-presented by the interviewer and interviewee together.

In regard to my actual interviews, I had a general list of themes which I hoped to be able to go through at some point with my research participants. The main themes were: 1) illness, 2) daily life, 3) relationships, 4) emotions, expectations, 5) worldview, and 6) death and dying (if the person seemed able and willing to talk about this). I approached these themes by asking various questions relating to them and evoking free conversation (in more detail on this, see Appendix 4). In practice, the list worked more as a memory aid for myself and a starter kit for the conversation. Since the moments with my research participants varied greatly (depending on their emotional, psychological, and physical condition), I practiced active and reflective listening and evaluated the situation, keeping their needs in mind. I facilitated the research participants to lead the conversation, and I usually avoided bringing up death and dying, since I wished to hear the way in which they would initiate the topic. Sometimes, after careful consideration, if I felt that the research participant was emotionally open to it, I would initiate the conversation about death and dying. Discussions of death varied in their emotional character, from very sad and serious to engaging in laughter and joking. I made constant assessments of the situation, and I was always ready to shift the conversation elsewhere if needed. In the end, however, conversing was only one facet of my relationship with the research participants, which comprised attending, caring, and listening.

3.3 Research ethics

Studying a vulnerable group of people

As Lawton (2001: 696) has pointed out, the paucity of (ethnographic) research among terminally ill patients is most likely intertwined with the ethical issues related to studying a vulnerable group of people (see, however, Krawczyk & Richards 2019). There are some discussions suggesting that palliative patients might need to be excluded altogether from academic research for being such a vulnerable group of people (Lawton 2001: 696; Pessin et

al. 2008: 628). For instance, palliative medicine consultant Fiona Randall and philosopher Robert Downie have questioned whether research consent can really be given voluntarily by the terminally ill, since due to their vulnerability and increased sense of dependency, they may feel coerced to participate in a study (Randall & Downie 1999: 242). They have further remarked that the dying patients should enjoy their remaining time "in peace," in the company of their loved ones, rather than being bothered with questionnaires, for instance (Randall & Downie 1999: 242). Other possible risks have been mentioned in the research literature, such as invasion of privacy due to vulnerability or distress, inclusion of overly personal questions, and physical stress associated with the completion of interviews (Pessin et al. 2008: 628). All of these are valid concerns, which were considered carefully before and during the ethnography (as explained in detail below).

The critical perspective has been challenged by others who claim it to be patronizing (Lawton 2001: 696; Corbin & Morse 2003). Compared to medical trials, for instance, in qualitative research the participants retain a considerable degree of control over the research process (Corbin & Morse 2003). A study conducted by psychologist Hayley Pessin et al. (2008) precisely on the effects of psychosocial research on palliative patients found empirical support for the view that research participants can actually benefit from the participation. The study also confirmed that palliative patients do practice their agency; for example, they dropped out of the research if they found it to be too strenuous for them (Pessin et al. 2008: 630). To make an assumption that a person with palliative status is too vulnerable to be part of research is to take authority and agency away from the very group it would be best to learn more about. That would also imply a practice of control of "what is said, how it is said, or if anything is said at all about the topic" (Corbin & Morse 2003: 337). Studying groups of people who are economically, physically, socially, ethnically, or sexually marginalized has always been important for social sciences such as anthropology or the science of religion, and ethnographic research can be seen as a form of politics of recognition (Taylor 1994). There is a great deal of research about end-of-life care, as well as public discussion and even debate on how it should be organized (on euthanasia, see Jylhänkangas 2013), but seldom are the perspectives of those in the core of the discussion brought forward or researched. From an ethical, political, and scholarly point of view, it is critical to give a voice to those who are often voiceless.

In the article "Benefits of Participating in Research Interviews" written by Sally Hutchinson et al. (1994) in the field of nursing science, giving a voice to the voiceless and disenfranchised was listed as one of the possible positive aspects. The other possible benefits mentioned were to provide self-acknowledgement and validation, contribute to a sense of purpose, increase self-awareness, grant a sense of empowerment, and promote healing (Corbin & Morse 2003: 346; Pessin et al. 2008). Of these, having a sense of purpose seemed especially important to many of the participants in my research, given what they shared with me. Similarly, in her seminal

study *On Death and Dying*, Elizabeth Kübler-Ross acknowledges how the patients interviewed by her research group responded positively:

> The majority of patients welcomed a breakthrough of their defenses, and were relieved when they did not have to play a game of superficial conversation when deep down they were so troubled with real or unrealistic fears. Many of them reacted to the first meeting as if we had opened a floodgate: they poured out all their bottled-up feelings and responded with great relief after such a meeting. (Kübler-Ross [1969] 2009: 209)

A similar response was given by Inkeri, an interviewee who remarked that our meetings had "great meaning" for her. She said that it was "energizing" to be able to reflect on things in this way, that it was bringing up "the real dimension [of the experience], that there is no pretending or making up anything" (Inkeri/2). In general, I experienced that there was a need to be heard (Frank 2000). Scholar of qualitative research methods and psychologist Steinar Kvale has pointed out that the very act of talking with another person who is genuinely interested in your viewpoint can be a rewarding experience (Kvale 1984, cited in Corbin & Morse 2003: 339). Some of my research participants explicitly wished to share their story with a wider audience and "send their greetings" (Finnish: *lähettää terveisiä*) to others (most often to the medical staff).

In addition to an augmentation of agency, some research discussions may even have therapeutic value for participants (Lawton 2001: 696). This seemed to be the case for some of my research participants. One participant, Heidi, exclaimed after our first discussion: "Wow! That was a good experience. Somehow so purifying… It was like some sort of religious ritual!" (D1: 104). This comment reflects what Hutchinson et al. (1994) have referred to as catharsis, one possible reaction to a sensitive interview on an emotionally loaded topic. As nursing science scholars Laura Dempsey et al. (2016) note, sensitive topics such as death, dying, loss, and bereavement require a sensitive, reflective, and attentive style of interviewing. Although there are risks to be taken into account when this sort of study is taking place (such as how to proceed if the interviewee has an emotional breakdown), there is no evidence that sensitive interviewing causes harm to interviewees (Corbin & Morse 2003; Dempsey et al. 2016). Thus, even though researchers may not be counselors, the interview process can become therapeutic for the attendants (Holloway & Wheeler 1995, cited in Dempsey et al. 2016).[78] At the same time, there are always ethical aspects and risks, and this is also true with sensitive interviews when researching palliative patients.

I received very few negative responses when approaching patients. Few declined my research request, stating that they had "nothing to say" to me. In regard to negative responses during the research process, sometimes patients became emotional, to be sure. While they

[78] In regard to the status of the volunteers in the hospice, sociologist Michael R. Leming: "As a stranger who provides a 'listening ear,' without emotional involvements or professional entanglements, the volunteer can support the patient and his or her family members in a way that no other participants in the social network of dying can" (Leming 2003: 488).

experienced challenging emotions, this usually did not lessen their willingness to be part of the research. Only one of the research participants, Susanna, wished to interrupt the research after several months of participation. We had had one interview, and she agreed that I could use the material that I had collected until then (D4: 21). I never asked her why she wanted to quit, but I did get the impression that the complex emotions that my questions brought up were difficult for her, and she did not want to go through them in my presence. Such ethical issues need to be considered and dealt with thoroughly during the whole research process, starting from the research plan and during the ethnography itself, including the final research report.

Research ethics applied

The general ethical guidelines and principles regarding the methods of this research follow those given by the Finnish National Board on Research Integrity (TENK) (2009) for human sciences in Finland.[79] The ethical principles can be divided into three areas: 1) respecting the autonomy of research subjects; 2) avoiding harm, and 3) privacy and data protection. I will first go through these briefly in regard to my research, and then I will continue to explicate those ethical aspects of the medical research (also applicable to my research, since I did research in medical sites).

Respecting the autonomy of research subjects

Participation in the research was completely voluntary. When I was recruiting patients in the university hospital and the hospice home, the staff placed announcements about my presence on the walls of the facility, explaining that I might approach patients in order to ask about their potential interest in the study. All of the participants were well informed about the content and implementation of the study, both verbally and in written form. For approval of their participation and also to give consent to use their personal data, the research participants were asked to sign a research consent form (see Appendix 2). In order to respect the autonomy of the researched individuals, I continued to verbally verify the patients' willingness to continue with the research, even after I had a signed research consent form from them.[80] I made sure that the researched knew that they had right to ask me to leave any given situation at any moment, or to interrupt the whole research process, if they so wished.

Avoiding harm

Harm that any research might bring about can be related to the three different phases of the research: collecting the research material, guarding the material, and the actual research

[79] Here the term "human sciences" is used to differentiate research in the social sciences and humanities from research in the medical sciences. Medical research applies a different set of ethical guidelines, which are based on the Finnish Law Medical Research Act 488/1999. The TENK guidelines were updated in 2019; this study applies the older version of the guidelines.

[80] In general, human sciences do not always require written research consent from the research participants (oral consent can be sufficient in certain types of research), yet in cases of sensitive topics, vulnerable research groups, or institutional settings such as hospitals (all of which applied to my study), it was deemed appropriate to verify the voluntary participation and document it well.

publications. As explained above, the material collection was planned carefully in the research plan, and the ethical approval from the university hospital's ethical board was applied for and granted before the fieldwork. Given the sensitive topic and vulnerability of the research participants, extra caution was taken during the material collection. I prepared myself for the various possible kinds of situations and reactions that I could encounter at the field. I practiced sensibilities continuously in order to evaluate the research situation from the point of view of the researched individual, and if I sensed tension or uneasiness, or if the researched participant started crying (which happened a few times), I stopped recording (if that was taking place) and offered emphatic support. Usually these kinds of difficult moments passed by simply giving participants time and space, allowing them to recover without interference. Since my interviews were very loosely structured, it meant that the participants could lead the conversation, deciding which themes to include and which to leave out, and how fast or slow to proceed with sensitive topics. I supported the conversational direction that the interviewees wished to take; sometimes I would gently guide the conversation, but the research participants generally played the central role by telling their story the way they wished (see Corbin & Morse 2003: 339). All the meetings happened on the patients' terms in relation to the places and moments they chose.

During the research process, the research material was handled with care and stored according to the guidelines stated by TENK.[81] In regard to research reports such as articles, presentations, and now this dissertation, I have carefully considered the manner in which I write and the way I present various details about the field.[82] I have practiced respectful writing, meaning that I have sought to understand the situation from the research participant's perspective, and I have not disclosed any information which could be interpreted as derogatory to any parties involved. However, the results of research may not always please all the participants or some parties involved in the research process. From an academic point of view, it would be equally unethical not to publish important data out of excessive consideration or fear. If I ever encountered a situation in which conflicting interests arose, I sought to do what I thought would be most beneficial for my research participants. Furthermore, since the topic of death, dying, and the care of the dying can easily trigger a variety of reactions, personal memories, or opinions in the public, the whole research process requires extra thoughtfulness on the part of the researcher.

Lastly, in regard to the style of writing, it is notable that different fields of scholarship use different styles of writing. The literary and reflexive style of writing is often attributed to anthropological and ethnographic texts (Clifford and Marcus 1986). Ethnographic writing is in

[81] Paper material was stored in locked archive cabinets in a locked office room at the university and the electric material was stored in the university's safe storage area in password-protected files.

[82] In terms of writing the reports, TENK says: "Researchers should avoid any damage or harm to subjects that may be caused by research publications. However, this principle should not prevent the publication of research findings that may not be pleasing to subjects in all respects. A researcher's task is to produce new information without having to fear the reaction of authorities or other research subjects. Particularly research concerning the use of power and the functioning of social institutions must not be restricted on the grounds that results can have negative effects for subjects" (TENK 2009).

the details; furthermore, the reflexive dialogue between the ethnographic material, the theories, and the author is brought forth since it is a way to construct the argument.

Privacy and data protection

The study observes the regulations set out in the Finnish Data Protection Act (1050/2018). It protects the privacy of the research participants and those who may appear in the research indirectly (for instance, in the speech of the interviewees). The research material, which includes information that can be categorized as belonging to the special categories of personal data (i.e., religious conviction and health), has been stored throughout the research process in a protected place according to the regulations. Upon the completion of the study, all of the research material has been stored in the Umpio storage space for sensitive data at the University of Helsinki.

Throughout the research process, I have practiced a high degree of confidentiality in regard to the information gained during my ethnographic research. As medical sociologist Benjamin Saunders et al. (2015) observes, anonymity is a form of confidentiality; in practice this means that the identities of the researched are kept hidden from anyone outside of the research team. Since I often recruited the patients with the help of the nursing staff, this aspect of the data protection was not always possible. However, I never discussed of the information given by my interviewees to the staff, and in my written reports their identities are blurred so that the persons are not recognizable.

Pseudonymization[83] in the social sciences is often taken for granted, yet there has also been debate about the fact that there are sometimes participants who wish to be recognized, and who should be given credit for their input in the research (Boylorn 2012). Especially in the field of anthropology and gender studies, it has become common to regard the information produced in the research as engendered through the joint effort of the researcher and the research participants. Depending on the epistemological stance taken by the researcher, the participants can be interpreted as collaborators, thereby earning the right for their names to be mentioned, in some cases even as co-authors of the research report (Boylorn 2012). Some of my research participants did wish to be presented by their own names, and for some the issue did not matter.[84] However, because my research design was evaluated by the medical ethical board, for whom the identity protection was absolute, I did not seek to negotiate this question any further.

[83] There is a debate whether complete anonymization is ever possible in qualitative research (Saunders et al. 2015). Usually, however, data can be regarded as anonymous if the identity of a person is not traceable, directly or indirectly, in any possible way, not even by combining different pieces of information together. Legally speaking, this sort of anonymization is achievable only after the identification codes used in research have been destroyed. Since in this research the identification codes and the research consents are saved and stored (in the Umpio storage space for sensitive data at the University of Helsinki), all the data in my research report is legally regarded as *pseudonymized* (see https://tietosuoja.fi/en/pseudonymised-and-anonymised-data).

[84] Pseudonyms can be seen as patronizing and as denying the agency from the research participants; yet often the researcher is required to anonymize the research material. If an issue, the participants can be called to choose their own pseudonyms (Given 2008). I explained the necessity of the pseudonymization practice to everyone, and all the research participants agreed with it.

The only exception consists of two blog writers, who wrote with their own names and made their identities public also in other ways in the media.

There are a number of technical methods to encrypt identifiable information for the research report. The pseudonymization process is a balancing act for the researcher: while on one hand one seeks to ensure full protection of the participants' identities, on the other hand one needs to maintain the value and integrity of the data (Saunders et al. 2015). Saunders et al. (2015) have identified six categories of data, which are in focus when research needs to modify information to guard the identity of the research participant: 1) people's names, 2) places, 3) religious or cultural background, 4) occupation, 5) family relationships, and 6) other potentially identifying information. As different studies focus on different research questions, not all studies can follow exactly the same procedures; for instance, when studying issues explicitly relating to religion, it is impossible to alter information pertaining to that category. In that case, some other set of information can be altered more in order to support the lack of identification.

In regard to this study, all the *names of the research participants* as well as their family members' names have been altered (with the exception of the bloggers who wrote under their own names). Rather than using numbers or other codes for my research participants, I followed the standard practice in anthropology and applied pseudonyms for them (Given 2008).[85] In some cases, I have not mentioned which of my research participants I am talking about. This is also a conscious choice, which intends to blur some of the personal information regarding the patients. In regard to other personal data, the question of *age* was somewhat important to my study design; in the research report, however, I only give the rough ages of the participants (within the range of a decade) instead of revealing their exact ages.

The question of *places* is also important. Since one of the specific research interests has to do with the issue of place and space, I refer to different places quite a bit. When doing so, however, I include only those details critical to my analysis. The living locations of my research participants, for instance, were not usually important, and they are not reported. The actual research sites are mentioned, but in the text I refer to them as the "hospice home" and the "oncology ward." It is important to emphasize here that many of the participants talked about various (other) medical sites and care locations where they had been prior to their current situation. When writing about these references embedded in the interview accounts, I use the generic terms of "hospital," "ward," or "clinic" without any further specification about the exact location. It is not of importance in this study, which focuses on the patients' experiences rather than the research sites themselves. This practice also protects the identity of the staff members in these various locations. Moreover, to further protect the identity of my participants, I use a

[85] Some social studies use numbers to code interviewees, but this solution has never been popular in anthropology, probably because the practice can have a depersonalizing effect in regard to the participants (Iphofen 2013: 43). Pseudonyms can be seen also as patronizing and as denying the agency of the research participants, yet often the researcher is required to anonymize the research material. In that case, the participants themselves can choose their own pseudonyms for the study (Given 2008).

loose timeline when discussing events and encounters with the patients. In this way, even if the place could be identified, the exact times of the meetings are concealed. I may also blur some sequences of events in order to enhance anonymity.

While the question of *religious conviction* was key for my study, as mentioned previously, I was not so interested in the official status of a person (whether they were officially a Lutheran or belonged to a Jewish congregation, for example). Instead, I bring up religiosity and spirituality as they come up in the interviews—and in those terms. This was certainly one main interest in my study, and it needs to be discussed. This can be done when other personal information is more blurred.

Occupation was significant at times. For instance, if a patient had previous experience in medicine because of their occupation, it usually affected their perception of their situation. Within the limits of data integrity, I have generalized the categories[86] (for instance, midwife → medical profession) and modified some details of the occupational information in such a way that they are not traceable. *Family relations* were also rather crucial in my study, but those are mentioned only if they appeared in the conversations in a noteworthy way. When the family members are mentioned, details that do not interfere with the analysis are blurred (e.g., sex or exact age of children). Lastly, *medical diagnosis* is an important bit of information that could potentially be used to identify a research participant. At times, it did not matter for the research what kind of cancer the patient had. In other cases, however, it was fundamental to how the patient had experienced themselves, their body, and their illness trajectory. If I needed to alter the information or even leave it out altogether for the sake of protecting identities, I did it in such a way that it would not compromise the analysis.

Confidentiality also means that the researcher exercises her sensibilities in regard to the kinds of information that have been shared with her. There were things that I learned and things that I was told about which never ended up in my research reports. I made a decision to leave them out, usually out of courtesy or the need to protect people's identities. On the other hand, I disclose certain things that may be difficult, embarrassing, or uncomfortable to read about. The potential discomfort of the reader cannot prevent me as a researcher from writing about matters that were true to those who shared them.

[86] To protect the participants' identity, I refer to their jobs by utilizing the current version of the International Standard Classification of Occupations (ISCO-08), from which I apply the abstraction level of *sub-major groups*. (https://en.wikipedia.org/wiki/International_Standard_Classification_of_Occupations).

4. RESEARCH PROCESS, RESEARCH MATERIAL, AND METHOD OF ANALYSIS

4.1 Research sites

Intended and realized research sites

The original plan was to find research patients at four sites: a day hospice and the actual hospice ward, both at the hospice home, and an oncology ward and the palliative care unit of the oncology department, both at a university hospital. In the end, patients were recruited mostly from the hospice home, and only two patients from the oncology ward were included in the final analysis. Furthermore, while I had planned to do similar kinds of ethnography at the oncology ward and at the hospice home, for several reasons this turned out to not be possible. In some cases this related to simple practicalities; in others it had to do with the nature of the care the respective places offer.

First, patients visited these medical sites with differing intentions. Day hospice offered a supportive place to visit regularly, as long as the patient's condition permitted. The hospice ward was sometimes visited to assess medications, but most often it was the place where the research participants died. Although sometimes the visits at the hospice ward were short, most often they lasted several days. In terms of the research, it was possible to meet the same patient several times, first in the day hospice and later on at the hospice ward. Most of the patients who came to the oncology ward (with 23 beds) did so for their oncological treatments, such as the administration of cytotoxic drugs or radiotherapy; complications such as infections, pain, and anemia were also treated there. Because of the acute nature of their medical problems, the time spent there was short. Furthermore, it was not always possible for me to verify the status of the care strategy of a particular patient. Although I found it easy to make contact with patients on the oncology ward, at the hospice home those contacts lasted longer, and therefore it was easier to involve them in the research.

The second main reason for my concentration on the hospice home in the end has to do with the nature of the care in these two research sites: the hospice home is by definition for palliative and hospice patients and the oncological ward is mostly for acute patients. With 45–50 deaths per year, the nature of the care at the oncology ward was mostly curative, at times disease-modifying, and more rarely palliative. For this reason, most of the patients I met there were not palliative patients, the sample I was seeking to recruit. In the end, however, the research sites became above all places where I found my research participants, whom I then continued to meet in the various locations where they were: at the hospital, at the hospice ward, or at home.

The plan to gather additional research participants from the palliative care unit of the oncology department at the university hospital was never actualized. It proved to be practically challenging to recruit patients there, since they went to the unit only for a brief consultation visit, compared to the ward where I was able to become familiar with the patients over time. Furthermore, when the research process was in the phase when I could have started this part of

the fieldwork, I already had lots of research material gathered, and at that point I had existing research patients whom I was continuing to study. There was simply no need for an additional fieldwork site.

In the end, I spent only four weeks at the oncology ward, whereas I visited the hospice home regularly over three years. In this way, the hospice home, and especially the day hospice, became my primary research site.

Hospice home

The hospice in which I ended up doing most of my ethnography consisted of an actual ward with approximately 20 patient beds, a day hospice unit (with its own spacious room), and a home care team. The yearly utilization rate of the actual ward and the day hospice have fluctuated some during the last years. From 2014 to 2017, both the numbers of patients who died at the ward and the number of the day hospice visits declined by a few dozen. The time that dying patients spent at the hospice ward varied greatly, from hours to several weeks; however, the average time was less than 14 days.

The actual building in which the hospice was located is designed specifically for hospice use. The design largely follows the general architectural ideas of British hospice homes (Worpole 2010). The interior of the whole building is circular: the patient rooms are located mostly on the southwest side of the building in three wings facing an outdoor patio with flowers, whereas the north side is reserved for the staff's rooms and offices, and for the large day hospice gathering room. The passageway connecting the patient rooms and other spaces circles around the heart of the hospice, comprised of the kitchen, the common dining area, and a winter garden filled with natural light from large skylights.

The public entrance to the building is on the north side of the building, as it often times is at hospices (Worpole 2010: 46). In this way, most of the patient rooms as well as the garden (or patio) can be situated facing toward the rising sun and the south and southwest. After entering the building, there is a large foyer area with a sofa and a reception desk, connected to an office. This type of entrance reminds one more of a hotel than a hospital (Worpole 2010: 46). Patients, staff, and visitors enter and exit from the main public door, and there is another entrance for staff. Patients who are admitted to the hospice ward usually exit through "the back door," that is, the door of the chapel on the east side of the building, where the mortuary is located.

In the field, there was a general feeling that the nature of care had changed during the last 20 years. Some of the medical professionals in the hospice home felt that the care had become more medicalized than before (D1: 30–31, 87; D2: 69). A nurse with decades of experience in the hospice field was of the opinion that earlier the patients were in better physical condition and there was more social interaction with them; the nurse continued that nowadays the interaction happens more with family members, and actual patient care has become very different from twenty years ago. According to her, due to medical progress, patients lived longer than before; they could have multiple problems and severe complications due to their long

illness trajectories, which were often accompanied by many treatments. This in turn resulted in heavier medication toward the end of life (D1: 30–31, 87). Even though the nature of hospice work had changed a lot, the nurse still wanted to emphasize that "this is still hospice care, as the care given here is patient-centered, in contrast with hospitals where the care is always system-centered" (D1: 30). Another experienced nurse felt that patients have less ability today to face the kind of inevitable existential crisis that dying brings to the surface; thus, rather than trying to treat the problem via discussion, anxieties and existential crises tend to be quickly responded to with drugs (D1: 87). These opinions are based on the personal experiences of healthcare professionals, but they also reflect the countercultural nature of the original hospice movement and the somewhat ambiguous relationship between the hospice and hospital that still seem to prevail in the field (Lewis [2006] 2011: 6).

In practice, the development of the palliative care system in Finland explains some of these changes. Since new palliative units and wards have been opened, the less challenged palliative patients can now be treated elsewhere, and the hospice home has become a care location for patients who are medically more demanding. Furthermore, like elsewhere in the field of healthcare, the emphasis nowadays is on homecare, meaning that more patients seek to be cared for at home until their death.

These changes in the practices have affected the usage of the space in the hospice home. For instance, ALS patients (the most prominent new patient group today) require more space due to the various adaptive equipment that they require. This was not taken into account in the building's original floor plan. There is also quite a bit of general traffic in the house. During my ethnography, I met students from various educational units, a few reporters, a group of documentary filmmakers, and even another researcher at the hospice home. In addition, the hospice ward is increasingly used for short-term visits by homecare patients needing to adjust their pain medication, for instance. This seems to be an international trend among hospice homes, as Worpole (2010: 42) points out: "The one-way door has become a revolving door, and to some extent the hospice which was only a short while ago configured as an intimate and quietist antechamber to death has become more like a village fête where people come and go…"

Many of the patients who are admitted to the hospice ward are already in very weak physical condition, and thus they have limited ability to enjoy the hospice space. One day I was touring the hospice home with a newly admitted couple (the husband was the patient). Both were very pleased with the aesthetic details of its decor and decoration, and they remarked how lovely and thoughtful everything seemed to be. After a little pause, the wife continued hesitantly: "but all of those beautiful couches and nice sitting areas were empty of people, so I guess that means that the patients are already in such a bad condition that…" The nurse who was with us confirmed: "Yes, it is mostly the family members who get to enjoy all of this." This led to a small silence, but the couple nevertheless concluded that they felt that they would be safe at the hospice home (D4: 5–6).

When I was at the hospice home, I spent time mostly in the day hospice room and in the general areas of the winter garden and common dining space. Once I was familiar with a patient, I also visited their room. I hung around the backyard, where some patients would go for a smoke, as that was often an excellent moment for a conversation. I ate my lunch or dinner in the nurses' area, which offered some interaction with the staff. In general, I was on good terms with all the staff, from the cleaners to the office personnel.

4.2 Research process

Fieldwork phase I—the first ten months

As planned, I first set out to study the day hospice group, which gathered once a week in the hospice home. Since at that time I lived a two-hour drive away from the city, this was the most convenient and practical way of starting the fieldwork. Getting to know the hospice home via the day hospice group felt like a good way to become familiar with both the staff and the patients. I did my intense period of ethnography at the hospice and hospital ward during the following summer, when my family temporarily moved to the city.

In the day hospice

Once I started the fieldwork with the visits to the day hospice group, I continued these visits regularly for the next eight months. My role at the day hospice was much like that of the hospice volunteers. I wore the same vest as the volunteer workers, but a patch on my chest also gave my name and identified me as a "researcher." I helped with some small practical things, such as offering food or clearing the table, but mostly my "job" was to converse with the patients. For the first few months, more or less the same five to seven patients, plus one or two volunteers and two nurses and I, kept meeting on Tuesdays. Hence, I started calling our group the "Tuesday crew." Majority of the patients were women, a common feature in different kinds of support groups, but usually there was also at least one or two men. Sometimes a new member would join the group and someone else would die, but there were four members who remained for several months. In this way, there was some cohesion and familiar dynamics in the group. Due to general changes in the organization of the care, during my fieldwork the time of the Tuesday meeting was later changed to Monday and then again to Friday. Concurrently, the total number of members in the group diminished.

During the first spring, I steadily followed six patients: Irma, Rauha, Aili, Oiva, Siru, and Taina. Irma and Rauha died first, a few months after the beginning of the research. The other four continued to be part of the research for several months, Siru and Aili even for years. I continued to visit these patients in the day group, but later I also went to their homes and the hospice ward, once they were admitted there.

At the hospice ward

As planned, later on that year I started my fieldwork at the main ward of the hospice. Again, I was presented much like the volunteers, and I wore the same orange vest with my name patch. In addition to this, the hospice ward had notifications (small posters on the walls) informing about the presence of a researcher on the premises. From my previous visits to the day hospice, I already knew some of the staff and the volunteer workers; now I met the rest of the staff. I was welcomed to the ward very openly overall, but naturally there were differences in the staff's attitudes. Some were curious and open toward my work, whereas others preferred to stay in the background without too much of involvement. Throughout my time in the hospice home, I maintained close connections and had many insightful conversations with the staff members. During the first three weeks of the fieldwork, I stayed on the hospice ward for 6–8 hours at a time, at different times of day. Sometimes I stayed very late in the evening, but I never stayed overnight. Again, my role was similar to that of a volunteer; I chatted with people, both patients and family members, and offered general support and a listening ear to anyone needing it. Occasionally, I gave a hand to the nurses if they were busy; I would make beds or help with feeding.[87] At times, I would sit with a restless patient or talk with the family members. Because many of these situations were too acute or too intimate to initiate any questions about participating in the research, these experiences are not included in my material. In general, I worked under the same ethical guidelines as any other volunteer worker there. Everything that I saw or heard was confidential, and only after the patient had signed the research consent would I assume my role as a researcher and start making notes or recording conversations. In regard to recruiting the patients, I exercised sensitivity and only asked those individuals to join whom I felt would be comfortable to talk with me. In practice, it was often the nurses who suggested a particular patient to me. Over the following weeks, I started closely working with five patients: Eeva, Aurora, Kimmo, Heidi, and Peter.

I continued occasional visits to the hospice ward throughout the first year, since I wanted to keep in touch with my existing research participants. I also maintained contact with my day hospice research patients; during the summer break for instance, I would call them by phone and at times visit them at their homes. Later on that year, my main field site was the oncology ward at the university hospital.[88]

On the oncology ward

During the four weeks I visited the oncology ward, I interviewed eight patients altogether. During the morning report, the nurses often suggested some patients that I could approach for the research. After word of mouth about my research started circulating on the ward, some

[87] My role in the field was very similar to Utriainen's when she was conducting her ethnography on the role of women as caregivers for the dying (Utriainen 1999: 181–186).

[88] Earlier I had met with the head nurse and delivered all the required papers, such as the notifications to the oncology ward about my coming.

patients approached me, saying that they wanted to participate in the study. Even though some of these patients were clearly not receiving palliative care, since they so wished to talk with me I did an interview with them. On the oncology ward, I found my relationships with the research patients to be more centered around "the interview." I believe that this was because there was less of the kind of informal "hanging out" than at the hospice home, where there were usually always some people in the public areas, eating, reading a newspaper, or going outside for a smoke. Although I had signed research consent forms and engaged in a number of discussions with a total of eight patients on the oncology ward, I actively continued following only two: Pekka and Martti. This was because the others, as far as I understood, were not palliative patients and thus did not qualify as participants in my study. As far as I knew, Pekka was not formally a palliative patient at the time either, but since he told me flat out that he had been given only a few months to live, I made the decision to include him in the study. Martti introduced the topic of his possible death due to his illness on our very first meeting, so I included him in the study also. I kept in contact for a while with some of the others that I had met on the oncology ward. I called four of them a few weeks after our initial meeting, and I even met with one of them, but afterwards I did not maintain further connection.

By the end of the first summer, I had 13 research patients that I was following closely. I kept going back to the day hospice, and I visited my research participants at the hospice ward. I started meeting Pekka and Martti at their homes, since they were no longer in the hospital. When our family moved back to the countryside, I kept driving to the city once a week to meet with my research participants.[89] Simultaneously, however, my mother's condition had gotten worse, and I needed to be with her more. Around the same time, some important research participants—Peter, Kimmo, Heidi, and Oiva—died. Since I had been able to meet with all of them before that, I felt a sense of closure. Meanwhile, even though I did my best to maintain and manage all of my important connections, I felt inadequate, both as a researcher and as a daughter. Everything changed when my mother died in the autumn.

Fieldwork and emotions—intermediate period of six months

My mother's death interrupted the course of my fieldwork for a period of six months. It not only impacted my emotional state but also the practical situation, since I had to take time off from my work to organize several practical matters with her affairs. I knew that some of my research patients were close to death, and I felt bad about not being in contact with them. Since I was not able to make my way to the weekly meetings of the day hospice group, I called the hospice nurse in charge and let her know about my situation. A couple days later, the mail brought me a condolences card signed by everyone in the "Tuesday crew": the patients, the nurses, and even the car driver with whom we shared morning coffee in the group. When I talked about this later on with the nurses, they told me that the patients in the group had

[89] Later on, my family again moved to the city, and my work in the field became much easier.

accidentally overheard the reason why I was not attending, and that it had been their idea to remember me with a card. This gesture is telling in regard to the kind of relationship I had with my research participants. And yet, it also marked a change in the dynamics of our relations.

I had always considered my relationship with my research participants reciprocal, but my personal loss inevitably shifted my position in the constellation vis-à-vis the others even more in that direction. The nurses now approached me from their professional position, since in their eyes I was a grieving family member. Prior to this, we had been more like colleagues or even friends (later on, after the acute phase of grieving was over, the relationship returned to that). Patients, on the other hand, were taking a consoling role toward me, as I had become the fragile one. This was moving, of course, but I was aware that this could be burdening to the patients. In short, rather than being the observing yet empathic professional researcher, I became the vulnerable, grieving daughter. It was a strange position for me, and I decided to take some time off from the fieldwork.

Although the situation was rather complex, I believe that my personal experience with my mother ultimately deepened my understanding of the research participants. Because of the intimate encounters with my mother, it was perhaps easier for me to relate to the general physical and emotional distress that advanced cancer can cause (however individual those experiences might be). The personal involvement also affected the way in which I saw my research overall. Unlike my research participants, my mother was not referred to palliative care. This enabled me to see the difference that palliative care can have on a patient's end of life, which in turn reinforced my understanding of the importance of palliative care, especially in regard to its accessibility. Furthermore, later involvement in hospice education gave me a larger perspective on the state of palliative care in Finland, and I learned that my mother's situation was not so uncommon. I realized that my research group represented a rather specific, and perhaps even exceptional, group of dying patients. It is also possible that my experience with my mother sensitized me to some of the less successful facets of care, which I was told about by my research participants during my fieldwork.

Three of my research patients—Eeva, Taina, and Pekka—died during my absence from the field. This was sad to me, especially since I felt that there had not been proper closure with any of them. These kinds of emotional aspects of ethnographic fieldwork have been examined by various anthropologists (e.g., Davies & Spencer 2010). It is generally acknowledged that due to varying power dynamics, and due to the differing expectations that people who are involved in research have, relationships between ethnographers and research participants are always multifaceted and emotionally complex (Davies & Spencer 2010).[90] Emotional, empathetic encounters and recognition of the other person (based on acknowledgment of the differences

[90] In particular, as discussed in the conference *Wild or Domesticated*, sentiments of guilt are common for anthropologists. Anthropologist François Bouchetoux (2014) has written about the matter in a very insightful manner.

and commonalities one has with them) function, however, as the ethical basis for a relationship, including those in the field (Smith & Kleinman 2010).[91] Hence, being aware of one's emotional state, one's feelings of responsibility, empathy, and guilt comprise an important and valuable facet of the fieldwork (Smith & Kleinman 2010: 173). Ultimately, recognition of the complex reciprocities and multileveled nature of the various dynamic relations—both within the field and in-between the field, academia, and the personal life of a researcher—is connected to an epistemic understanding of the world, in which interconnectedness is accepted as a factual feature of reality.

Although out of reciprocity I occasionally shared some aspects of my private life with my research participants, I was careful never to talk about anything that could cause anxiety or burden them in any possible way.[92] Consequently, I never told them about my mother's illness. When my mother died and the whole Tuesday group learned about it, I decided to be honest with them about my feelings. I did not, however, want to burden my research participants with my personal life situation, and for the sake of regaining my emotional balance in order to be able to work properly in the field, I needed to stay away from the field for some time. I was gone for almost six months altogether before I returned to the field.

From my research participants I had learned that patients did not always share everything with their loved ones, and now I learned from my mother that the patient did not always share everything with outsiders—be they doctors, therapists, or researchers. In this way I knew that there were probably things that my mother did not share with me, and yet I learned things with her which I could not have learned with the research participants. Furthermore, since my mother was never referred to palliative care, with her I witnessed not only a different kind of care trajectory but also a different kind of patient trajectory. This brought me a valuable perspective. My mother agreed that I would also write about her, although I think that for her (like for many) the topic was a strange and gloomy choice for research. In the end, my involvement in end-of-life research was perhaps beneficial to her, since I was familiar with some practicalities related to advanced cancer, and we could discuss these issues in more detail.

Fieldwork phase II—the last two years

When I returned to the field the following spring, I continued to attend the Tuesday meetings of day hospice, not every Tuesday but regularly enough to follow my research participants. Over the next two years, I gained more research participants: Kirsi, Kristiina, Inkeri, Vivian, Helena, and Susanna (the latter dropped out after one year of participation).[93] I also started following two blogs written by patients with advanced cancer: Marjo-Riitta's *Syöpä tarinoituu*

[91] Here I refer to "the other" simply as another person. There are various interpretations about what is exactly meant with the word 'Other' in phenomenology (see Large 1996).
[92] Reciprocity is seen as a prerequisite for doing a sensitive interview (Corbin & Morse 2003: 339).
[93] I met with most of these patients many times, except for Kirsi, whom I only met twice. In addition to these research participants, I had signed consents from three other patients in the day hospice; however, those individuals died before we ever really got to talk with each other.

todeksi and Heikki's *Sairaan rakas elämä*. I met both Marjo-Riitta and Heikki later on, and they agreed to be part of my study. At this point I was not actively seeking any more research participants, since I assessed that the material I was getting was already sufficient. A year later, I made an exception and included one more patient, Matti, since there was a wish from his side to be part of the study. He was the last participant that I included in the research. Given the abundance of the research material, I did not feel the need to return to do further systematic fieldwork at the hospice ward or oncology ward. I was following the trajectories of my research participants, and if they were assigned to a ward, I kept visiting them there. In this way, over a three-to-four-year period I met with my research patients in various locations, such as a nursing home, hospital wards, and the hospice ward, of course. Most of my research patients died at the hospice home.

For some patients, it seemed especially important to be able to "contribute still something to academic society."[94] Other participants had similar thoughts, but they were framed differently. Instead of seeing the research as something scientifically important, they stated that they wished to do something beneficial for others who were in a similar situation. In other words, they hoped that my research would make a difference in regard to some of the difficulties that they themselves had encountered during their illness trajectories. At the same time, the participation seemed to bring personal delight; perhaps it added some variety to the sometimes monotonous days. Some simply seemed to enjoy the chance to reflect on things with another person. This was clearly evident on the hospital ward, where I once even found a line of patients waiting to have an interview. Only one participant, Susanna, decided to interrupt her participation after a year for personal reasons.

4.3 Research material and the method of analysis

Number of research participants

I had planned to recruit 40 research patients: 20 from the university hospital and 20 from the hospice home. As explained above, this plan for recruiting the research participants changed in the course of the ethnography.[95] It was easy to find willing participants from the research sites. Furthermore, when word about my research had gone out to the field, I received three requests from people who asked to participate in the research themselves or suggested that their loved one might join in. One of these people I had known previously, but two of them came via other connections by word of mouth. Since my relationships with many of the research participants lasted for months and grew deeper over time, in the end I had an abundance of research material.

I had underestimated the amount of research material that could be gained from just one single participant. During the course of my fieldwork, I received altogether 31 signed research consents. Of those, three patients died before I had a chance to talk more with them, six proved

[94] This view was also expressed by Kristiina, an academic whom I met several times at her place of care.
[95] This is not unusual for ethnographic studies, rather the opposite; since ethnography deals with complex realities with multiple unforeseeable factors, in practice the research plan may need to be modified.

to not be palliative patients, and one patient turned out to be otherwise unsuitable for the research. In the end, therefore, I had 21 research participants: 14 women and 7 men (for the list of the research participants, see Appendix 3). Of those 21, two were recruited from the oncology ward, fourteen from the hospice home, three came via common acquaintances, and two via blogs.

Research participants and the research material

The general criteria for the patients to attend the study were: 1) being over 18 years of age, 2) belonging to palliative (including hospice) care, and 3) being able to communicate. In practice, it was not always possible for me to verify the patient's official care strategy (i.e., palliative care), but since most of my research participants were recruited from the hospice home, de facto they were palliative patients. For the patients themselves, the exact labels and definitions of curative, disease-modifying, palliative, and hospice care were somewhat unclear; however, the moment when a patient was appointed to hospice care often marked a very significant passage for them.

All of the research participants had been diagnosed with cancer. Some had multiple forms of cancer, while others also had additional diseases that complicated their situation. The participants were mostly from urban areas in South Finland, although a couple lived in the countryside. The ages of the participants varied from 45 (at the moment of the joining the study) to 84 years old. All of the researched were native Finns, but socioeconomically their backgrounds varied greatly. Among the participants there were, for example, teaching, engineering, and cultural professionals; business and administration associate professionals; and service workers, drivers, and care workers. Many of the participants were members of the Evangelical Lutheran Church of Finland but did not consider themselves as religious, or they considered themselves to be religious "in a typical Finnish manner."[96] One of my research participants described this by saying that: "I am just like the others, I believe a little bit—but not really, however" (D1: 93). In addition to members of the Church, and a couple who did not belong to any organized religion, my research group otherwise represented a variety of Finnish religious traditions: there was one Orthodox (Greek), one Conservative Laestadian, and two who came from a Pentecostal background. Furthermore, one participant was an active member of a charismatic Christian congregation, and another self-identified as a born-again Christian. Although this might suggest a strong presence of religion in my material, interestingly enough, in most cases these religious affiliations or denominations did not seem to significantly affect their metaphysical interpretations or mental attitudes in regard to death and dying. With the exception of three patients (Siru, Martti, and Pekka), I experienced people's (non-) religious views to be dynamic, fluid, versatile, and momentary.

[96] See Chapter 3. Teemu Taira (2012: 23) writes that "in terms of beliefs, the Finns are neither very religious nor explicitly atheistic"; he also writes that the general religiosity of Finns could be defined as "belonging without practicing, since the Church membership is still high in Finland but most people do not practice religion in any way" (Taira 2015).

Due to various (mostly practical) reasons, I spent much more time with some individuals than with others. In the end, my most frequent meetings and lengthiest conversations happened with twelve of the research participants (their names are in bold letters in Appendix 3). Many of the conversations that I had with the patients were never recorded; some were casual and random discussions that did not relate to the study at all, but others involved a moment with the patient that became so intimate and delicate that taking notes or starting to record would have been inappropriate. At the end of the fieldwork period, I had 51 hours of recorded conversations with patients. It was not possible to transcribe all the material; instead, I went through the material a few times, making literal transcriptions of most of the interviews, some in their entirety and others in relation to specific statements or themes. In addition to making a digital recording, with certain patients, such as Kimmo, I preferred to write notes. While my choice of documentation depended especially on my assessment of the situation which the researched participant was in, it also depended on their general style of communication.[97] I had four field diaries, three handwritten ones and one digital one, which I would use when at the office. Those diaries together contain about 350 pages of text. In addition to this, my research participants shared some photos with me (for instance, of places that were important for them). I was also given quotes from poems and books that had been meaningful for the patients, and so forth. Of the two blogs I was following, I saved the pages and sections that I used in my analysis into separate files. Together, all of this material played a part when I was creating a coherent picture of the lived reality of my research participants.

In addition to the patients, I also talked with staff, especially the nurses, volunteers, and priests. A few times I also met with the family members of a patient. I found this to be an important gesture, especially if I had spent lots of time with their loved one. I used some of the material in the blogs for my analysis, since I had met the authors and they made up part of the research.

Ancillary research material

In addition to the actual primary research material, I collected ancillary material, which mostly comprised general data regarding palliative care and issues relating with the end of life. This collection includes newspaper articles, reports, and memorandums by the Social and Health Ministry, and so forth. I also attended seminars and conferences on death and dying and hospice care, both as an attendee and as an educator.[98] In these seminars, I not only met many experts in the field but also people with various sorts of experiences and testimonials of end-of-life

[97] I did not record my conversations if a participant had, for instance, a very long-winded or rambling way of talking, which resulted in lengthy monologues that did not necessarily have much relevance for the research. With some of my research participants I had the impression that loneliness, which sometimes had lasted for years, caused this sort of reaction toward me and my research. I decided not to record other participants because their expression was very short and emotionally inhibited; in these situations I concentrated more on nonverbal communication.
[98] I have given lectures on culturally sensitive care and rituals of death and dying in different religions.

care. This helped me to create a general picture of palliative care in the whole of Finland. During the years 2016–2017, I attended a special training program for hospice educators, which was funded and organized by the Common Responsibility Campaign's Good Death project.[99] The group of trainees consisted of palliative doctors and nurses, along with other professionals working with various aspects of hospice care all around Finland. I learned also a great deal from these meetings, and I heard various perspectives on palliative care in Finland. This ancillary material helped me to better understand some issues that had arisen in my research material. I learned more about the staff's perspectives and experiences in regard to end-of-life care, and it is likely that this information has also colored my overall understanding of the care situations. I found it crucial to talk with experts working in the field, since palliative care has seen a period of dynamic change in Finland over the last ten to fifteen years, and even during my research project many things changed.

About the method and process of analysis

The method of analyzing qualitative research material needs to be in accordance with the epistemic underpinnings and theoretical approaches applied in the study as a whole. Since my research material was comprised of interview recordings, transcripts, photos, blog texts, and other texts, such as quotes by poets, it was not possible to apply one single method of analysis. My task was to try to understand how my research participants understood and experienced their realities (i.e., double hermeneutics; see Smith & Osborn 2003). The best way to reach this understanding was to apply abductive reasoning to my research material. Abductive reasoning differs from deductive and inductive reasoning, which are commonly used in scientific research. Sociologist of religion Vida Bajc (2012) describes the manner of doing abductive ethnography in the following way:

> Ethnography is best suited to the study of multiplicity, complexity, contingency, ambiguity, and indeterminacy in ways of living. It allows a researcher to choose for analytic attention specific instances of human activity and experience that show potential to illuminate conceptual issues and to stumble upon particularities of social life that alter our theoretical understandings. Theoretically interesting social activity can be identified using Peircean abduction. Rather than following a predetermined set of research questions in the data collection process, abductive ethnography embraces serendipity and allows intuition to guide the fieldwork. Data analysis begins neither with inductive nor deductive reasoning. By temporarily disassociating the data from their context, specific theoretical debates, and the experience of data collection in the field, the ethnographer is able to play with the data freely and let this process lead to a surprising discovery and insight. This discovery is then conceptually articulated through the dialog among the insight, contextualized empirical evidence, and theoretical knowledge. (Bajc 2012: 73)

Abductive reasoning implies that the researcher's processual thinking moves between the actual research data, her own experiential insights from the field, and the theoretical reasoning, leading

[99] Known in Finnish as "Yhteisvastuukeräys," this is a nationwide social movement and annual fundraising campaign of the Finnish Lutheran Church (https://www.yhteisvastuu.fi/en/the-common-responsibility-campaign/). In 2014, one of its objects for fundraising was hospice education.

to enriching, heuristic, and continuous knowledge formation. In practice, this required a theoretically and emotionally unprejudiced, open frame of mind while gathering the data. Although to some extent my initial research questions guided my attention in the field, I conducted my ethnography as an anthropologist who brackets her own previous understanding and assumptions about reality and seeks to encounter the other with an open mind (Desjarlais & Throop 2011). I was not necessarily expecting to find exact answers to the questions I had; furthermore, I was prepared to encounter entirely different aspects.

All of this served to shed light on the issues which were not talked about. Absence is one kind of presence. I had a similar insight regarding the *doing* of things (i.e., rituals). Instead of simply remarking that there appeared to be almost no rituals of preparation for death and dying, I began to look at existing actions and practices from the point of view of ritual theory. This led to the insight that many actions that were done in the proximity of death were actually charged with awareness of the coming death. Something that I had not even imagined to look for prior to my fieldwork was the theme of aesthetics, which pushed me toward the "surprising discovery and insight" that Bajc talks about above.

I practiced rigorous dialogue between various theoretical approaches and my findings from the field; I wrote tentative papers on these themes, which I presented at various academic conferences in Finland, Great Britain, and the United States of America.[100] I was also seeking to find ways to write about emotionally strong encounters and the existential shuddering that I witnessed at times; here I leaned mostly on philosophical formulations. While the process of analysis was ongoing all the time, from the beginning of the fieldwork, it fluctuated. There were moments of total immersion in the field when I sought to merely connect with my research participants without too much interpretation, and then at times I withdrew into the theoretical research literature in order to make sense of my field experiences.

Once my fieldwork came to an end and I had all of my interviews, with the transcripts and the field diaries and notes in front of me, another kind of analytical phase began. On one hand, I already had certain themes and insights in my mind, which I now sought to explicate through my research data (see Bajc 2012: 83). Among those were various relationalities of place and space (such as nature), death talk, medicine, the body, and aesthetics. Yet, in order to find new insights from the conversational material created together with the research participants, I drew from the system of interpretative phenomenological analysis (IPA) developed especially by psychologist Jonathan A. Smith et al. (Smith & Osborn 2003; Smith et al. 2009).[101] The IPA

[100] These included *Art Approaching Science and Religion* in Turku in May 11–13, 2016; the 13th Conference of *Death, Dying and Disposal* (DDD13) in September 2017 at the University of Central Lancashire, UK; and the Dying and Bereavement Interest Group of the Society for Medical Anthropology at the *Annual Meeting of the American Anthropological Association* (AAA) in November 2018 in San Jose, California.

[101] The IPA method, which Smith et al. developed in the field of psychology in the 1990s but which has since spread to various disciplines in human, social, and health sciences has its theoretical roots in phenomenology, hermeneutics, and idiography (Smith et al. 2009). The phenomenological ground of IPA emphasizes the exploration of experience on its own terms and the hermeneutics highlights an interpretative approach toward

method "is committed to understanding how particular experiential phenomena (an event, process or relationship) have been understood from the perspective of particular people in a particular context" (Smith et al. 2009: 29), and as such it has been used widely in qualitative healthcare research (Biggerstaff & Thompson 2008; Smith & Eatough 2019). Since IPA focuses especially on the question of how people ascribe meaning to their experiences in their interactions with the environment, it has offered a multifaceted and nuanced understanding of how experiences in the realm of healthcare can vary depending on the perspective. Thus, it has been "especially suited to studies that aim to relate findings to bio-psycho-social theories that dominate current thinking within the healthcare profession" (Biggerstaff & Thompson 2008).

I applied IPA methods loosely.[102] Nonetheless, they describe well the most essential features of the process of analyzing the material. I did careful reading and re-reading of the transcripts (and other texts relating to the field). I listened to the recorded material in order to remember my field experiences. I was looking for recurrent phrases and themes having to do, for instance, with the emotions, experiential claims, concerns, and understandings expressed by the research participants. I took notes on them and looked for emergent patterns and clusters of themes. I also made notes on how patients talked about things, what kinds of choices of expressions and words were made, and what other types of communicative modalities may have arisen in certain situations. In this way, I proceeded by looking for connections and relationalities between the themes that arose: issues relating to (loss of a) authority, shame, hope, trust, structures of time, and relationships with the surroundings and medical staff. An important feature of IPA arises from the idea of the hermeneutic circle, which concerns the dynamic relationship between the part and the whole. The process of analysis is iterative and it requires constant evaluation of the relationship of any particular single part (e.g., a word, sentence, interview, or episode) to the whole (correspondingly, a sentence in which the word is embedded, complete text, the whole research project, or one's whole life). As Smith et al. (2009: 26) put it: "To understand any given part, you look to the whole; to understand the whole, you look to the parts." In this way, the process of analysis contains continuous shifting and refocusing of perspectives. I also practiced reflective engagement with the participants' accounts, as Smith, Larkin, and Flowers depict the process: "Inevitably, the analysis is a joint product of the participant and the analyst.

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experience. The idiographic approach emphasizes particularity rather than the nomothetic, generalizing tendencies of the natural sciences. In short, IPA is "a qualitative research approach committed to the examination of how people make sense of their major life experiences" (Smith et al. 2009: 1). As a methodological system, it offers detailed guidelines for doing research in a qualitative frame, from the principles of research design and data collection to the methods of analysis (see Smith et al. 2009). Many of these methodological tools are akin to those traditionally applied by anthropologists and others doing ethnographic research.

[102] Smith et al. (2009) describe a detailed and structured strategy for conducting solid analysis, yet they also remark that IPA is not about following some exact steps but utilizing them in a creative manner depending on the material and the experience of the researcher (Smith et al. 2009: 80–81). However, the analysis (as described in Smith et al. 2009: 81–107) generally comprises the following procedures: reading and rereading the research material; initial noting, including descriptive, linguistic, and conceptual comments; developing emergent themes; searching for connections across emergent themes; and, finally, looking for patterns across cases. As such, the method of analysis resembles thematic analysis in qualitative research.

Although the primary concern of IPA is the lived experience of the participant and the meaning which the participant makes of that lived experience, the end result is always an account of how the analyst thinks the participant is thinking – this is the double hermeneutic" (Smith, Larkin & Flowers 2009: 81).

From an ethnographic point of view, Smith's IPA method is a systemized depiction of the kind of methodological analysis that anthropologists and ethnographers have traditionally done with their interview materials. In an ethnographic study, the IPA method can provide only part of the analysis, since it handles only the interview material; ethnography itself is a much larger endeavor, as I described above in relation to abductive ethnography. In the end, for a scholar of culture and religion, inclusion of the larger context and its various affective relationalities to the participants' experiences must be introduced to the analysis, which includes notions from all the different micro, meso, and macro levels (see Figure 8.)

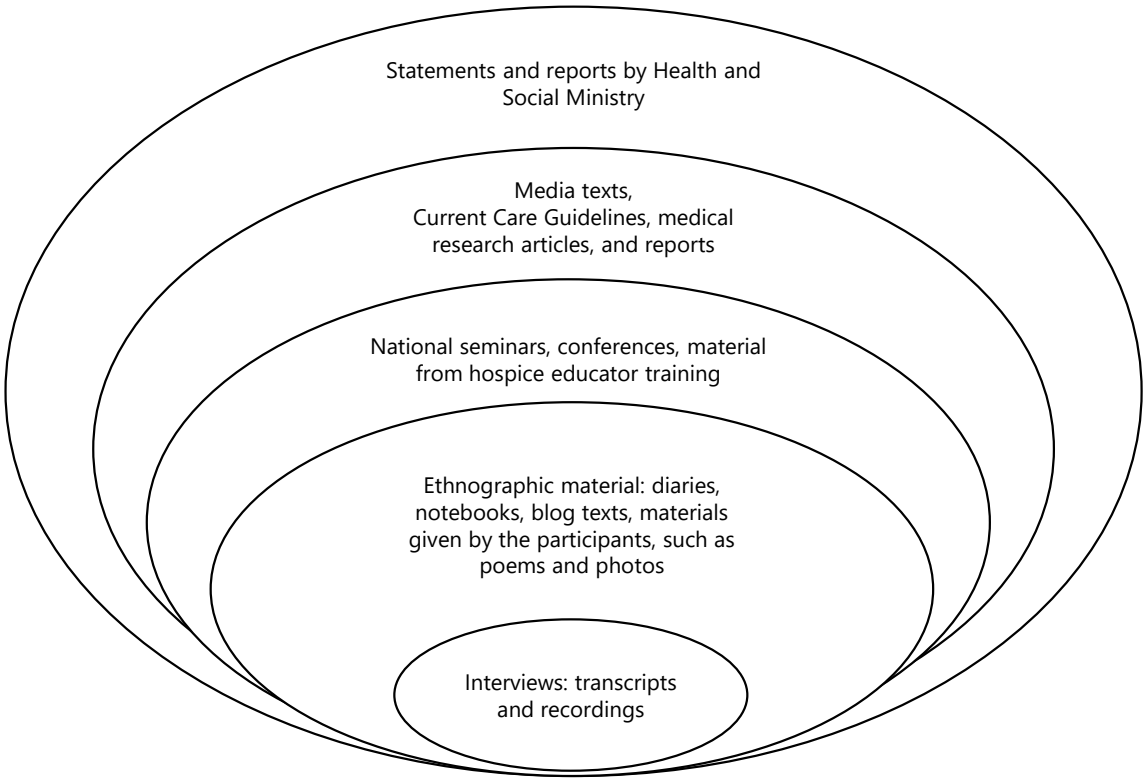

Figure 8. The research material, including the ancillary material, in relation to micro, meso, and macro levels.

PART II – THE DISRUPTED LANDSCAPE

The first section of my analysis starts by depicting the ways in which serious illness and the threat of imminent death appeared in the landscape of life of my research patients. I will describe a variety of emotional responses and reactions, which the diagnoses and prognoses caused, and how difficult it often was to talk about death. I will contemplate the meaning of space and place for sick and dying patients. The places and structures in which dying patients encounter themselves significantly affect the way they experience their end of life.

In the latter part of this section, I look at how rationales of care practices emerged in my research participants' accounts. Since healthcare policies and practices shaped actual illness trajectories and the experiences my research participants had, it is necessary to include some of those factors in the analysis. I will look at the medical relationships in which my research patients found themselves, and examine some issues relating to communication. At the end of the section, I will consider the difference between the hospice and curative medical frames by means of Deleuze and Guattari's concepts of smooth and striated.

5. EMERGING LANDSCAPES OF DEATH

5.1 Death in the landscape of life

Death on the horizon

> Wednesday morning the phone rings again, and I recognize the doctor's number. I know already what to expect when I answer the call. The results from the pathologist have arrived, and unfortunately my tumor is malignant. I thank them for the information; there is nothing else I can think to say or ask.
>
> Time stops. This very cliché expression turns into truth for me. I feel like I am but without really being. Where is the horror handle that I could grasp onto? Where?
>
> I am calm and in panic at the same time. I go for a walk, and I call my spouse and the father of my children, different men. At some point, a restless animal starts moving inside of me, and I would like to climb into the train again, to go somewhere, anywhere. Away, away, away.
>
> Anxiety rises like warm water up my legs, filling me slowly. When it has risen to my lungs, I cannot breathe anymore—I drown. (Marjo-Riitta, blog post, 12/29/2012)[103]
>
> ***
>
> It was during the chemotherapy, a routine consultation, like one of those when you go and see the doctor before going to the treatment. I thought it was just a routine thing. So I went there by car. But then… my [tumor] markers were suddenly elevated. And that was a sign that the [treatments] were not working. I was not prepared to hear that it was going to be chronic, that I would not be cured. And then I heard it. It was told, and then they chucked me out. It was one of those half-hour or twenty-minute appointments… And "this is chronic now, and you won't be cured of this"—and out. And then I drove home. Luckily nothing happened, because I was not in driving condition at that moment. I really needed to focus, yet I drove the wrong way. It was really dangerous to go driving in that situation. (Vivian/2)

Hearing about a diagnosis of serious illness or a terminal diagnosis can be a dramatic disruption in life's landscape, as something new—and often scary—abruptly appears on the horizon.[104] In the quote above, after Vivian learned about her cancer being incurable, she literally lost her capacity to orient herself in traffic while driving home from the appointment. In Marjo-Riitta's description in her blog, the usual laws of nature seem to disappear, time ceases, perception shifts, and the grasp on reality is lost. When death appears on the horizon, it may capture one's

[103] "Keskiviikko aamuna puhelin soi uudestaan ja tällä kertaa tunnistan jo puhelinnumerosta lääkärin soittavan jälleen. Tiedän jo mitä odottaa vastatessani. Patologin vastaukset ovat tulleet ja valitettavasti kasvaimeni on pahanlaatuinen. Kiitän tiedosta, mitään muuta en osaakaan sanoa tai kysyä. Aika pysähtyy. Tämä hyvin kliseinen ilmaus muuttuu minulle totuudelliseksi. Tunnen olevani kuitenkaan olematta, missä on kauhukahva josta voin ottaa kiinni? Missä? Olen rauhallinen ja paniikissa samaan aikaan. Käyn kävelyllä soittamassa miehelleni sekä lasteni isälle, eri miehiä nämä. Jossain vaiheessa alkaa joku levoton eläin liikkua sisälläni ja haluaisin taas vain junaan, ihan mihin vaan, kun vaan jonnekin. Pois, pois, pois. Ahdistus nousee kuin lämmin vesi pitkin jalkojani täyttäen minut hitaasti kokonaan. Kun se on noussut keuhkoihin saakka, en pysty enää hengittämään - hukun."

[104] In phenomenological discussions since Husserl, the term "horizon" has been used to refer to sensed perception happening from a certain embodied and situated standpoint, both in a concrete bodily sense and in a mental or cognitive sense (Vessey 2009). The horizon can also be used to depict the cultural and historical situatedness from which a person approaches and seeks to apprehend life.

attention in such a way that it permeates the perceiver with paralyzing force while everything else falls into the background.[105] There can be a momentary cut in the sense of relationality altogether: Marjo-Riitta describes how terror rises inside of her like water, threatening to drown her. She becomes isolated from her usual environment and there is nothing to grasp onto. Learning about a terminal condition shakes the core of one's being and ruptures what Merleau-Ponty ([1945] 2005: xx) has called operative intentionality; all previous plans and practical intentions disappear, and the embodied relation to the world and being itself becomes altered—and ultimately threatened. Like Marjo-Riitta writes, "I *am*—but without really *being*."

Vivian was a patient in her fifties whom I had met at the day hospice, and she talked about her paralyzing fear almost every time we met. She told me that soon after her initial diagnosis, she had seen the image of her death (Vivian/1). "It was like a tsunami that comes and wipes everything out," she described, "like the one in Thailand where so many people died because they did not even think to escape from it." She described to me how at first, when she was in the hospice home, the tsunami swept over her every hour; later it happened once a day.[106] A year after the diagnosis, the tsunami only hit her rarely; yet, there was still no "picture of solace" (*lohdun kuvaa*), she said (Vivian/1).

When a terminal diagnosis emerges on life's horizon, it reminds of something theoretically acknowledged but perhaps never thought of or seen before. Even though nothing has really changed with the world, for most people the world has become a different place. Paradoxically, sometimes all that one can think of is some banal detail of everyday life:

> When I went into shock, I tried explaining this [to the doctor]. It was like the priorities disappear, and the head is suddenly full of all kinds of things, big and small. And those things don't relate to each other in any way. […] There can be some completely ridiculous things, some totally irrelevant things, like happened to me. I thought, there is this bill I need to pay. Oh my God, here I go now. I may die anytime in the next few hours, and [all I can think of is] that I should have taken care of that bill! (Vivian/2)

How intensely this rupture happens and what sorts of emotions one experiences depend on many factors, such as age, worldview, personality, and one's life situation in general, as we shall see. The interesting thing with a horizon is that even though the vista itself may not change, a different view can be gained by changing one's position. For some of my research patients, this moment of learning about their approaching death marked the beginning of an active, new positioning in regard to the horizon and landscape of life and death. In contrast, others kept insisting on and simply wishing for a change in the horizon itself.

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[105] Paradoxically, without the background of life one would not even notice the appearance of death. In Husserl's and Merleau-Ponty's writing, horizon becomes more of a condition or background against which one is able to sense the world in the first place. As Merleau-Ponty ([1945] 2005: 78) writes: "I direct my gaze upon a sector of the landscape, which comes to life and is disclosed, while the other objects recede into the periphery and become dormant, while, however, not ceasing to be there. […] The horizon, then, is what guarantees the identity of the object throughout the exploration…"

[106] Vivian was first sent to the hospice ward, as she was in quite bad condition. Her medication was adjusted and she was able to return home. After receiving additional treatments from a private hospital and then home care for a year, she returned to hospice, first to the day hospice and eventually to the ward where she died.

Learning about the diagnosis and entering the medical path

Many of my research participants (Aili, Eeva, Peter, and Heikki, among others) entered onto their medical paths by going to see a doctor for some unusual—or unusually persistent—health problem. Some, however, came to learn about their health problems rather accidentally. Taina, a pensioner in her sixties, went to see a doctor after her pharmacologist urged her to do so; for months she had been buying bottle after bottle of cough syrup for a persistent cough. Only a few patients, like Eeva, told me that they had suspected something serious at this early stage. For most, the seriousness of their diagnosis was a surprise. A number of patients found it difficult to really comprehend and identify with the diagnosis, especially if they did not feel very sick yet. The sense of disease sometimes came slowly, and often the seriousness of the situation unfolded only gradually.

The diagnostic process—from the moment of making the first doctor's appointment until the moment of receiving a diagnosis and the commencement of treatments—can take weeks, or even months (e.g., Helena/1; see STM 2010b: 26, 52–53). It has been estimated that more than 30% of cancers are "harder to suspect," and their diagnosing often requires multiple consultations and various kinds of diagnostic testing, such as laboratory tests and imaging technology, all of which takes time (Lyratzopoulos et al. 2014). However, the delays in the diagnosis can also be due to the overloaded healthcare system, where the lack of free appointment times can lead to an inordinately long wait for consultation.[107] On the other hand, people may deliberately—although perhaps unconsciously—put off visiting a doctor, even when they have a chronic health problem.

One of those people was Heidi, whom I met several times at the hospice. When I got to know her, she was already bedridden, yet otherwise in high spirits. I was actually interviewing her roommate when I met her for the first time, upon her arrival at the hospice ward. I had been in a pause in the interview with her roommate, and so we started all chatting together. I explained who I was and what I was doing, and I asked her if she would like to join the study. She was happy to join the research, so I gave her the research information papers and set up a meeting for the next day.

In our first interview, when I asked how she found out about her diagnosis, she laughed darkly. She said that she *could have* gone to see a doctor some ten years before for her intense stomach pains. In the end, however, it took several years before she did:

> Heidi: Next month it will be two years since […] I was stretching and yawning and I thought, aha, now there is pain in the neck. Of course, I had had neck pains and shoulder trouble, like every office worker has. But my neck had never really hurt and then one evening it hurt immensely. I continued working for three and half months even after that, however…
>
> I: Did you go to some tests at that point?

[107] For recent statistics describing the waiting times for general healthcare, see https://sampo.thl.fi/pivot/prod/fi/avo/hpaasypth01/summary_pthrapo2.

> Heidi: I did. I went first to see our occupational doctor, who ordered me some X-rays, but nothing was showing in them […] I got into the CT scan… and (lowering her voice) the fellow said to me, once it had gone through there, the picture, that there seems to be many broken bones… (starts whispering) How there can be broken bones…

At this point in our conversation, Heidi's voice had become a mixture of whispering and tears. This was obviously a painful memory for her, yet, she continued her story. From this moment, it took another month before the cause of the fractures was found: a metastatic growth in the spine due to advanced cancer. Heidi admitted that she had ignored the early signs of the disease (such as the stomach pains) for a number of years. The tumor was several centimeters large when it was found, so it was apparent that it had been there for a long time. When Heidi told me about this, she cried. When I asked her why she thought she never went to a doctor earlier on, she simply noted that "there was always so much to do—life was busy." Later in our conversation, Heidi confessed that this whole thing—the diagnosis and all the sentiments around it—was something she seldom had talked about. She continued:

> Based on what I have talked about with some peer patients, it seems quite common, the idea that one shouldn't bother friends and family [with this kind of thing]. Although you ruminate on this thing constantly, it is there somewhere in the back of your head. Even if you don't think about it all the time, it is there anyhow. (Heidi/1)

I concluded that our conversation had offered a rare opportunity for Heidi to express her feelings, which she summarized in a seemingly stoic way by saying "Well, nothing to be done. There's no crying over spilled milk."

The period after the initial contact with a specialist and the actual final diagnosis and commencement of the cancer treatments can be a challenging time for the patient.[108] After Helena had her tumor operated on, it took another five weeks for her to hear about the results from the pathologist. Helena described this waiting period as exasperating (Helena/1). Although the quality of public healthcare (especially in regard to cancer) was highly appreciated among the research participants, there was also some dissatisfaction related to being able to access it. Kimmo, a lung cancer patient in his fifties, once commented on the Finnish healthcare system by saying, "Finnish healthcare is great—once you get in. But in order to get there and to start receiving proper care, you need to actively ask for information and demand care" (D1: 83). This remark reflects Kimmo's experiences about the communication and information-sharing with the doctors.

With many of my research participants (such as Oiva, Inkeri, and Vivian), the referral to palliative or hospice care was given after multiple medical phases, at a point when the disease had developed from a treatable cancer into an incurable disease with an expectation of little remaining lifespan. After a long illness trajectory including various treatments, the moment of

[108] For a news article on this, see https://stm.fi/artikkeli/-/asset_publisher/syopahoidon-aloittamisen-viiveita-pyritaan-lyhentamaan. About the reasons for the possible delays, see Mäklin & Mäkelä 2008.

hospice referral was often described by the research participants as the moment where "nothing more could be done."[109] With others (like, for instance, with Matti or my mother), the terminal nature of the sickness was clear from the outset and the first moment of the diagnosis; here the sudden prognosis came as a complete surprise and terrible shock. Yet, even when one was already diagnosed with cancer, and had been perhaps ill already for a while, taking a turn for the worse sometimes came as a profound blow "out of the blue":

> But then it happened that the doctor came to tell me the results of the CT scan. They had found some alterations in my lungs which seemed like metastasis. It came totally out of the blue to me![110] I had just expected to receive my treatments that day. But then it happened. The doctor just swept into the room and said, you won't receive any treatments today. You may have metastasis in the lungs. You can leave now. Go home and we'll get back to you… (laughter) I thought it was somewhat weird […] that now they don't give any chemotherapy, that you can go now! Isn't this the moment when you should give *all* the possible chemotherapies in the world!?! (Helena/1)[111]

> Then they called me [to say] that they had gone through my case in the team meeting and that indeed all the chemotherapy was now finished for me. That felt so very strange. That was the moment when my mom and everybody went into panic. (Helena/1)

Although receiving news about a serious disease or terminal condition was shocking to many, some patients took it more calmly. There are manifold reasons for the different ways of reacting to the news. According to a study from 2011, patients' reactions to "bad news"[112] are affected not only by the manner in which the news is delivered but also by the patients' prior experiences with the medical system; receiving the news was experienced as *a process* (Schaepe 2011). Another study—a large literary review on the topic—concluded that, in addition to the importance placed on psychological support, the patients (and their families) found the continuous relationship with the healthcare practitioner of utmost importance for being able to feel trust, have confidence, and experience a sense of nonabandonment at the moment of learning about their diagnosis (Matthews et al. 2019: 2292). Furthermore, the context of a person's life, such as age and family relationships, naturally affects the way in which they handle the situation. This does not mean, however, that older people necessarily receive a terminal diagnosis more easily than young people. Sometimes they do. For instance,

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[109] To raise public's awareness about hospice care, and specifically to express how hospice is *not* about ending all care, hospices use a common slogan: *Kun ei ole enää mitään tehtävissä, on vielä paljon tekemistä* ("When there is nothing more to be done, a lot remains to do"). See, for example, https://pirkanmaanhoitokoti-fi-bin.directo.fi/@Bin/10832ab157490e67a7f9c8ab5fd5bd85/1590463204/application/pdf/200008/PirHo_esite-web.pdf.

[110] As an interesting note on language, here Helena used the Finnish expression *puun takaa*, that something comes "from behind the tree," which means roughly the same as something coming out of the blue.

[111] Of course, we cannot know the exact exchange of words that took place in the consultation room. As I have noted earlier, the patients' quotes do not present depictions of reality in any objective sense; rather, they importantly illustrate the subjectivity of their experience and the subjective manner of interpreting, for instance, the communication with medical staff.

[112] In medical literature, bad news comprises information that "results in a cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received" (Ptacek & Eberhardt 1996, cited in Matthews et al. 2019). In common language, a doctor's bad news tends to be associated with a terminal, or at least very serious, diagnosis.

Aili and Matti—who were between 70–80 years old at the time of their diagnosis—were both understanding about their situation (although Matti added that since he had worked practically up until his diagnosis, he had missed his "third phase of life"). Yet, older people can also be very reluctant to face their mortal condition (e.g., Laakkonen 2005). Simultaneously, as nurses in the hospice pointed out to me, young people can be surprisingly brave in their ability to face the inescapable (D1: 36). In relation to one's life context, a factor that seemed to make a significant difference in the way that the news was taken was the possible existence of dependent family members. For instance, having small children, older parents, or a sick spouse who was dependent on the dying person made the thought of passing much more difficult—and, especially in regard to the children, often excruciatingly painful. My experience and impression from the field was that it was not uncommon for a patient to be most worried about their loved ones, compared to their own experience of dying.

In brief, the reactions to a fatal diagnosis were very individual. Even though research has found certain elements that affect death anxiety (e.g., see Surall & Steppacher 2018), the affecting variables are multiple. Thus, age, gender, religiosity, or culture, for instance, cannot alone explain the varieties of reactions. With my research participants, there was one element, however, which tended to boost the capacity to receive the news. That was the individual's practical and/or existential understanding of death and dying gained during one's lifetime. The first reactions often seemed to depend on previous experiences related to sickness and, in particular, end-of-life care. As we will see in the following cases with Aili and Eeva, this culturally learned and individually appropriated capital was connected to practicalities, as well as the more spiritual side of the matter; these aspects were essential when people were faced with their own mortality.

Sense of shame and guilt

Aili was one of my very first research participants at the day hospice. When I met Aili for the first time, she had been living with her diagnosis for about six months. She was interested in my research and was happy to participate; we met many times during the ethnography, and in addition to actual interviews about illness, death, and dying, we enjoyed many conversations about life in general.[113]

When Aili and I discussed her diagnosis, it became clear to me that she had taken the news of her terminal condition in a resigned way. She told me how she had been feeling ill and weak for some time already, when one day "the shopping bags became too heavy to carry all of a sudden." After she fell down on the ground, she was taken to the doctor and sent for further tests. It took weeks of various kinds of examinations before the cause of the symptoms was found. Finally, an endoscopy revealed the tumor. The actual diagnosis as well as the prognosis were delivered to her by phone, but she said she knew by then: "I had guessed already. I knew

[113] When Aili was first diagnosed, she was given four months to live. Yet, sometimes the prognosis can be wrong. Aili survived her cancer and continues to live today, years after the diagnosis.

it in me. I knew that, here we go now…" (Aili/1). In addition to the symptoms, all of the examinations had convinced Aili—an experienced healthcare practitioner herself—that something more essential was wrong with her body. The horizon had started to change, and it came into focus with the doctor's words over the phone. This manner of receiving the news was not ethically recommended, yet at that moment any possible lapses in protocol were of minor concern to Aili; because of her professional background, she understood the gravity of her situation perhaps better than a layperson.[114]

Aili felt some sense of guilt in regard to her situation, and this was something that we talked about rather often, especially during the first year or so of our interviews. Only after some time went by did the guilt ease its grip, and Aili became more forgiving toward herself. The guilt was accompanied by a sense of shame, which kept Aili from talking about it in a normal voice. Every time she would mention her earlier smoking, she inhaled the word "smoked":[115]

> Aili: I have this thing that I have smoked… It was a terrible thing. It was like I did it to myself!
>
> I: This was your first reaction?
>
> Aili: Yeah, that I did this by myself, that now I got my share, my pay from what I had done.[116] That I have been one of those slippery, dishonest persons who has acted as a… very good [healthcare practitioner] and like the caregiver for the whole family—parents, husband, grandchildren—and everybody, and then me, myself, I have done [this so] that my value, my value as a human, is gone.
>
> I had such a tough [attitude] that even if the world would come crumbling down, I should carry on (*jaksaa*). I always demanded a lot from myself. Maybe this was the kind of thing that I needed to do in secret… that I needed to reward myself. Quite an odd person. (Aili/1)

The word "slippery" was swallowed again with a whisper, as if Aili did not even want it to pass her lips. She was upset with herself, yet simultaneously she was somehow able to take distance from the issue. When telling me how she felt and thought, she clearly referred to *that time*, not the present moment of our conversation. This became evident from the way in which she described her feelings and thoughts: "…*that* I did it myself" instead of saying simply, "I did it myself." She was telling me a narrative from the past.

Over time, as I got to know Aili better, the more I understood how she felt about this issue. I also learned how very difficult it was for her to become dependent on others' help. In a way, Aili appeared as a sort of a national superheroine. First, she had survived World War II and its

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[114] The Finnish ethical guidelines for doctors state: "The doctor is usually the person who tells the patient about the approaching death. A peaceful place and sufficient amount of time are needed, so that the patients can discuss with the doctor without any disturbance. Illness and its prognosis should be told in a clear and understandable manner. The doctor needs to take into account the patient's ability to receive information and give him/her enough time to internalize the information that is given. It is advisable to arrange another appointment soon thereafter, in which the patient can ask further questions that may have arisen" (*Lääkärin etiikka* 2013: 152, translation mine).

[115] Speaking while inhaling is a peculiar feature of Finnish language (shared by some other, mostly Nordic languages). Although not constant, it can happen often, especially in combination with sensations of anxiety, fear, uncertainty, and so forth (Eklund 2008: 280–282).

[116] Aili here refers to a Finnish proverb: *Paha saa palkkansa* ("The evil will get its share"). This has a similar meaning as the English saying "What goes around comes around."

bombings in Karelia (once she told me how she needed to take cover behind a chimney wall from bullets being fired from a Russian fighter plane). Her family had lost their house and land, and they had suffered post-war poverty. From childhood on, she had known much hard work and experienced many personal losses. When Aili became an adult, she started working in the field of healthcare, taking care of everyone around her. She admitted that in her weakest moments during her illness, she sometimes thought to herself, "Haven't I had my share already?"

Aili's emotion can be understood through a perspective offered by Giddens, who claims that shame is "essentially anxiety about the adequacy of the narrative by means of which the individual sustains a coherent biology" (Giddens [1991] 2006: 65). Shame can be a very shattering feeling, since it threatens one's very self-identity, which Giddens ([1991] 2006: 53) defines as "the self as reflexively understood by the person in terms of her or his biography." Smoking was not part of Aili's self-identity, yet now she believed that she was suffering from its consequences.

Aside from Aili's internal turmoil, she took her situation very pragmatically. Because of her professional background, she knew how things would progress, and she shared honest and unsentimental conversations about her situation with her children. It seemed plausible that the general ease with which Aili faced the idea of death was due to the fact that she had frequently encountered it as part of her professional and private history. In other words, one could say that her professional and personal involvement with death and dying had given her resources which became valuable in a new way at this moment of her life. As one learns to live, one can also learn to die. This, I thought, became apparent with patients like Aili.

Nevertheless, the feelings of shame and guilt overshadowed the affective milieu where Aili was learning to bear the new horizon of death, which, according to the doctor's preliminary prognosis, was as near as four months away. As the general expectation of four months became four years and still counting, the shadow of the looming death still remained on the horizon but did not catch up with her. With time, Aili's condition changed from acutely terminal to chronic, and she needed to find new positionings in relation to death.

Death shirts for the family

Aili was not the only patient to tell that they already had a suspicion of being ill. I met Eeva during my ethnography at the hospice ward when she was referred there, after chemotherapy did not result in any improvement in her lung cancer. She had previously been in home care but was now admitted to the ward for a period of adjustment to the palliative medicine. The situation remained somewhat "unclear," she told me (D1: 63): the disease continued to spread and cause more symptoms, and it was necessary to continue adjusting medications. Eeva explained that the feeling of unclearness she experienced was in relation to time: she knew she would die, and the uncertainty about the length of the remaining time felt unsettling to her.

When I first talked with Eeva about her diagnosis, she stated laconically that even before going to the doctor she already thought, "Since I've smoked, I probably have cancer" (D1: 63). Consequently, when she was actually diagnosed with lung cancer, it was a mere confirmation of her rather apathetic expectation. For Eeva, cigarette smoking had never caused any significant emotional turmoil. Eeva was compliant and very "matter-of-fact" about her condition. The hardest thing was not the diagnosis itself but sharing the news with her child and their two adult children. Feeling touched, Eeva said to me: "It took me a while before I was able to tell them. And then when I did, I had to start consoling them all" (D1: 64).

Although not to the same extent as Aili, Eeva also had some prior experience of cancer and end-of-life care. Some years before, her sister had died and Eeva had stayed with her for the two last weeks, first at home and then the last week at the hospital. She told me, "That taught me to process these things" (D1: 64). As a Russian Orthodox, she had made a so-called death shirt (*kuolinpaita*) for her sister. In reality, it was a white linen dress with a small collar, open at the back. Eeva also made a lace hat, as her sister had lost her hair due to the treatments. Her mother had handed this tradition down to her. When Eeva's mother died, the daughters had washed and dressed her in the death shirt. Some years later, Eeva also needed to dress her sister. (D1: 65.) Now that her time had come, she prepared the death shirt for herself. In addition to the dress, she had also sewn underpants and an undershirt, and she had even knitted socks for herself.

Upon first hearing about the death shirt, I was shy to ask to see it, but later on, after getting to know her better, I asked about it. The shirt had first stayed at home but when Eeva's condition was getting worse, she brought it to the hospice ward so that it would be there, ready for her. One day she showed it to me. The white linen dress was waiting in a cardboard box, neatly folded with knitted white socks on top. By designing and making her own death shirt, she was exercising authority over her situation; in a way, she had literally designed her own "death style" (Davies 2015). She was managing her own dying and giving it the kind of frame she desired.

Making one's own death garment is an old Finnish tradition. If women tended to make their clothing for the journey to the next world, men would build their own caskets (Pentikäinen 1990: 69–70). Interestingly, these traditions have been revived during the last decades via courses and workshops where people are invited to either build their own caskets or design and make their own death garment.[117] Making one's own "death gear" can be seen as an empowering death ritual, where the dying not only think of their death but see it as a part of their life's horizon. In this way, one can design a desired landscape of death; it is one way to

[117] See, for instance, https://www.kirkkojakaupunki.fi/-/omalla-tyylilla and https://www.studio55.fi/matkailu/article/anneli-67-rakensi-oman-ruumisarkkunsa/129826. The first site informs about an exhibition of self-made death shirts, and the latter is an article on a course during which ten people (three women and seven men) made their own caskets. This is not very common in Finland, but not unheard of either. The article mentions that a German TV interview was done with the course members, since for that culture the idea of designing and making one's own casket seemed exotic.

take control of one's own final moments and even beyond. From a Spinozian point of view, here the dying person was able to be affected by and to affect death. Instead of death simply happening, Eeva engaged in empowering actions in regard to it. These kinds of rituals give the dying the ability to increase their power (*potentia*) to act in the face of death.

With Eeva, this active take on her situation was not limited to the death garment. Since the diagnosis, she had started to prepare herself in multiple ways. She knew how to *do* death. She talked about death-related matters with the family; after the deaths of her mother and sister, Eeva told me (D1: 64–65), they were all used to discussing these things. Of all of my research patients, Eeva was perhaps the most accepting about her situation. Here again, I could see how practice can teach one to accept death.

5.2 Trying to think and talk about death

"Just visiting the hospice home"

Being admitted to hospice care does not guarantee acceptance of the process of dying. I learned this with Peter, whom I met when he was sent to hospice for his worsening physical condition. Once he heard about my research, he promised me "a long, good interview," adding that he had "some things to tell!" (D4: 10). We signed the consent form and I accompanied Peter to the patio for a cigarette. Peter was thinking aloud about the patients around him on the hospice ward, remembering his experiences in the cancer clinic: "There they were, in a row, being all grey, next to one another, having given up." He shook his head, revolted. I asked him what he meant when he said that they had "given up." Peter answered, "Well, like, ready to… *die*. Let's use that [word] then, as that kind of word exists." It seemed self-evident that this was not Peter's position. By then, I had learned that Peter had a brain tumor. "It is all about your attitude," he said when I asked him how he was coping with his situation. "It totally depends on your attitude," he reiterated (DI: 43).

We agreed upon a day for our interview, but when the time came Peter had changed his mind; he did not want to speak with me, he said. I had been expecting this kind of reaction from the patients, but it actually happened less than I had imagined. A couple of days later, however, Peter was again ready to chat with me, and he told me his story. One evening slightly more than a year before, Peter had fallen down a few times, and he went to see a doctor. The doctor's initial thought was that there was a nerve problem in his leg, but just to be sure he sent Peter to a neurologist for further tests. Before any diagnosis ever came, he began having epileptic seizures. These left Peter with a hemiparesis, involving partial paralysis and weakness on the left side of his body. All this was terrifying to Peter. In particular, the first epileptic seizure had been a very frightening experience for this youthful business man, whose lifestyle, according to him, was about "luxury, trendy clothes, nice watches, and fancy restaurants" (D1: 58–59). Extensive imaging of his brain led to a clear diagnosis: glioblastoma, an aggressive type of brain tumor that offers poor prognosis. Even with proper medical treatment, only 20% of

patients survive two years (Mäenpää 2010). It is rare to be able to remove the entire tumor by surgery, and even if this is done successfully it usually reappears soon thereafter. Peter did not seem to care about these facts; instead, he had decided to survive this. He had had the brain surgery, which he talked about very calmly: "A visit to a dentist is scarier than any surgery in the brain." He told me that he was discharged only four days after the surgery. He returned home with some paracetamol for his pain, and otherwise he said he was living "just normally" (D1: 57–58).

Peter started to receive chemotherapy, first one kind and—after this did not seem to work—another kind. Little by little, the situation started to look much worse than Peter had ever dared to imagine. Now Peter was in hospice, according to him, to get his "medicines fixed"[118] for his worsening headaches. His personal goal was to rehabilitate his arm after the hemiparesis.

Although it was obvious that his cancer was terminal, Peter did not appear to care about or agree with the prognosis. This in itself was not unusual. As the medical literature explains, at times there is resistance against the diagnosis given by doctors, as patients, for multiple reasons, simply cannot be in accord with their medically defined condition (Gramling et al. 2016). Some of my research participants persistently claimed that they were given different facts about their illness by their previous doctor, and sometimes they asserted that they were not given any information at all about their situation. As Gramling et al. (2016: 1423) summarize: "communicating about prognosis in advanced cancer is not merely a straightforward exchange of information; it is affective and, when it happens, it occurs amid substantial uncertainty, confusion, and often terror." There are several possible reasons for this kind of discrepancy in patients' and doctors' understandings of the prognosis (Gramling et al. 2016). It is possible that the patient has simply not understood what they were told. Sometimes the language used by the doctor, or the sense of there being a rush during the consultation, makes it difficult for the patient to pose questions which would help to clarify the news. Often patients are in such shock that their capacity to absorb detailed information is drastically reduced (much like Vivian, explained above). It is also possible that the actual uttered words get transformed into something else in the patient's mind. Finally, of course, memory problems can also be a symptomatic feature, especially in the case of brain tumors.

In Peter's case, it may have been that his aversion toward bodily weakness fed his unwillingness to believe his actual situation. Death and decay were simply not things that belonged to his life horizon; he was not a "quitter" but a "man of action," he said to me (D4: 11).[119] During our interview, Peter repeatedly emphasized the difference between himself and the other patients: "As you can see, I am not any average patient, you cannot make me to be the

[118] As we will see, I was often told by the patients that they were at the hospice ward "in order to get their meds fixed." I never heard anyone say that they had come there for hospice care—or to die.

[119] In regard to death, Peter's orientation mirrors the argument of French existentialist Jean-Paul Sartre, who claimed that death can never become absorbed into one's lifeworld: "Death is a pure fact as is birth; it comes to us from outside and it transforms us into the outside" (Sartre 1956: 545). For Sartre (1956: 548), death is never part of one's subjectivity but rather the exterior limit of it.

median!" (D4: 11). Peter told that he had taken care of his situation quite independently. It all depends on your own activity, he assured me many times (D1: 43, 58). To me, it seemed like he was not only accentuating his authority over his situation but also differentiating between himself and the disease.

Peter practiced the "separation" also materially. His room on the hospice ward was filled with various tokens of his previous life: his iPhone and a large monitor for a computer (but no computer), a few empty cigar boxes, expensive-looking sunglasses, and a walking stick with a silver handle. These largely unused items created a contrast with their surroundings, the soft "homelike" hospice setting. This "hominess" (*kodinomaisuus*) is the most common adjective to describe hospice homes on the internet, both on hospice websites and in other media like newspapers. In practice, this "hominess" is pursued by furnishing the hospices with home-like furniture (such as sofa sets, book shelves, and art) and by creating various kinds of free areas inside the hospice home that patients can roam around. Of course, the "hominess" of the hospice environment is a matter of taste, and Peter was seeking an alternative by creating his own space. But whether one likes the hospice decor or not, the fact remains that hospice homes are also medical environments. By mediating his identity via his personal material symbols, Peter wished to separate himself from those whom he thought of as "grey, surrendered dying patients" (D1: 43). Peter sought to reinforce his identity with chosen items in order to contrast himself with a medically enhanced body; he chose not to be "the man with a walker" but rather "the man with a cane with a silver handle." As the disease progressed, however, it became more difficult to maintain this sort of self-identity.

In relation to being at the hospice home, Peter had a strong opinion: he hated it. When I asked what he hated most about the place, he fumed about the quiet and stillness, the fussing and pampering: "You should come here when it is nighttime." He continued: "All I hear is the sound of the neighbor's dental prosthetics, the fizz when he speaks! That's repulsive! (D4: 11)." When I asked Peter what he would do right now if he was not sick, he said that he dreamed of being 20 kg less (he was swollen from all the cortisone he had been prescribed), wearing some cool clothes and going downtown for a stroll with his cane. Then he would go to a fancy restaurant for a nice, proper dinner. Peter had been happy with his previous lifestyle and was now disgusted by his present situation. "I would like to be wearing a slightly different kind of watch on my wrist than this one!" he said, showing me the hospice alarm (D4: 11).

According to Peter, the ambiguity surrounding his current situation was the worst. To gain some clarity and perhaps some control over his situation, Peter told me that he had gone to a private clinic for a CT scan, and he was waiting for the results. When I checked his medical records after his death (in the company of a nurse), I found out that the CT scan had not been done at a private clinic but at the public cancer clinic as part of his care routine.[120] It is impossible to say if Peter created his version of the truth consciously or unconsciously. The

[120] My research permission authorized me to study the medical records of the research patients.

tumor naturally affected the way in which Peter experienced his situation (personality changes are commonly described symptoms of gliomas).[121] Since I am interested here in Peter's own account and the way he saw, felt, and thought about his situation, I take his words as depicting his actual experience. The idea of having some control over the situation and going to the private clinic for help made sense in Peter's lifeworld.

At the time of our interview, Peter's biggest problem was his paralyzed arm: "I just want to get my arm functioning, then go home and keep working" (D1: 58). Peter had told me about his future business plans, which he was eager to continue developing. Peter was very hopeful about his recovery; he was "just visiting the hospice home." He explained to me that his detestation toward being at the hospice actually motivated him to get better (D4: 11). He speculated about the results of his CT scan, saying that if there was something in the pictures he would let them operate again, but if the cancer had spread everywhere, then it may not be so wise. It did not seem to occur to him that the doctors perhaps would not *want* to operate on him again. By presenting the situation in this way, Peter perhaps sought to convince both himself and me that *he* was the one calling the shots.

Few days later, I met Peter again and we shared another cigarette moment on the patio. I had learned from the nurses that the results of his CT scan had arrived—and they had confirmed the spread of the tumor. I was waiting to see if Peter wanted to bring up the news, but he did not mention anything. Instead, he continued to distance himself from the terminal disease by othering the patients around him. Peter nodded toward another patient and commented to me, when she left the patio, that she was "*so* in her final [stages]!" Peter told me that at least three people had died since he had arrived at the ward. In reality, the number of the deceased at the hospice was much higher, but I simply nodded in agreement. (D1: 70–71.)

After this, we never again spoke about his condition, even though I did see him a few more times. We shared a moment for a cigarette, for instance, or just nodded to each other in the corridor. When his condition worsened, he stayed away from the public areas and a friend of his remained with him until his death. One of our last conversations exemplified his experience of the stillness of the ward. We were sitting by the main dining table in the great hall when Peter glanced at the antique grandfather clock on the wall. The hands of the clock were showing 8 o'clock. "Oh, is it so late already?" he asked, surprised. "No, it's not," I told him. "That clock

[121] The question of whether a feature of one's personality is really "authentically" a part of the persons' personality, or "merely" the result of a tumor or perhaps medication, is in itself somewhat problematic. First, as I have stated above, for me the subject is always constituted by various molecular mediations with the environment, whether concrete, physical, and chemical or social, psychological, and spiritual. Secondly, it is difficult to define what causes what—so here I am basing my analysis on the encounters I had and the way I experienced them. I am not in a position to definitively determine how "authentic" and "truthful" people may have been with me. My assumption is that whatever people shared with me, it was true, at least in that moment and for us in that situation.

doesn't run." The grandfather clock had stopped at some random moment. Hospice time was standing still, just like Peter's experience of it: motionless, liminal, quiet, and static.[122]

Later on, I kept thinking about this issue of *stillness*. The difference between life and death often seems to happen in relation to the question of *motion*. Motion equals life, while stillness relates to death. This appeared to be the case for some of the research participants: when their physical condition started preventing actual physical movement, forcing patients into stillness, many experienced this as signaling the beginning of the end.

To conclude, Peter chose not to look at death; rather, he kept his eyes on the horizon of life. Death did not make up any part of Peter's ontological world. Even if this was "just" the story he preferred to tell himself—or to me—it reveals how death, decay, and physical frailty had no place in Peter's lifeworld. (D1: 57–58.)

Seeking recovery

Peter was by no means the only one who had difficulties in accepting his diagnosis—and mortality. I would claim that acceptance of a terminal diagnosis was very hard for many of my research participants. Nurses at the hospice home recommended that I pay a visit to Kimmo. I gathered from the nurses' comments that they believed he would benefit from chatting with someone "from outside." Kimmo was a tall, quiet-looking man in his fifties. Kimmo had had a steady professional life until his diagnosis, and he was a husband and a father of teenage children. When I went to introduce myself, I found Kimmo resting on his bed, looking a bit shattered. He welcomed me and seemed happy to talk. I found him to be surprisingly open; it seemed like our meeting came at a vulnerable moment when he had just faced some difficult facts about his situation. He was in the kind of exposed, somewhat confused, and vulnerable state that I experienced with some other patients as well.

Kimmo had been diagnosed with lung cancer a little over a year before. The first signs of something being wrong had appeared 18 months earlier, when Kimmo was playing football with his friends. He suddenly felt dizzy and could not keep playing. Shortly after that, Kimmo fell ill with what seemed to be a very persistent flu. The doctors told him to take it easy and to rest. Finally, a few months later, Kimmo was sent for lung X-rays and from there straight to the hospital. The diagnosis was a terrible shock. Kimmo had never smoked but instead had led a healthy, sportive lifestyle. Hence, according to Kimmo, nothing had prepared him for this kind of situation.[123]

To Kimmo's relief, his condition was treatable. He was prescribed targeted therapy, which seemed to be very efficient; in just a week, Kimmo told me, all the symptoms had vanished.

[122]According to Finnish historian Leena Aaltonen (1992: 14–15), in rural Finland before World War I, it was a custom to wake with the dying. Everybody was told to be very quiet: "There was supposed to reign complete silence around the dying: even the grandfather clock needed to be paused."

[123] Many patients talked about the causes of their illness, or they demonstrated great interest in understanding *why* they fell ill in the first place. There was often astonishment when someone "who had led a healthy lifestyle" became ill. There seems to be a common need to make meaning in situations, which a biologist would explain merely as a simple occurrence of life and pure chance.

The new scans confirmed that the tumor had shrunk considerably, and Kimmo felt like he had conquered the cancer. It was a great summer, Kimmo remembered. One of the highlights was a holiday trip, which the family was able to make together. Soon thereafter, however, Kimmo became unusually tired again and he had alarming back pain. When he went for new scans, the results were devastating: the cancer had spread. Because of his positive experiences with the therapy during the last round, Kimmo felt optimistic. He had firm trust in the medicine, and he expected to be able to get back to work as soon as the chemotherapy was over. Yet, this time everything was different. Unlike before, now the treatments were very heavy, made him feel even sicker, and in the end did not diminish the tumor. (D1: 67.)

Kimmo's experience and interpretation of his illness and overall existence were strongly affected and mediated by medicine. The first time, drugs permeated his being in a positive manner, enabling and empowering him to live "normally" and enjoy his life fully. The second time around, the therapy turned out to be unsuccessful, and the medically mediated mode of being became excruciating. "The chemotherapy sucked all the life out of me," Kimmo said pensively when looking back. "I could feel it draining my muscles. All the power just flew away from them" (D1: 68). Kimmo was petrified, for he had always been a very active man. He had grown up in the countryside, and as he explained to me, "growing up on a farm means using your body for working and moving around" (D1: 72–74). He knew life as embodied movement.

It is possible to think that this was the reason why Kimmo fought back against the cancer first and foremost by exercising his body. In the course of the following months, he continued to keep himself physically active, even while becoming more frail and suffering from intensifying dizziness. As time went by, he said, the headaches became stronger and later a tumor was found in his brain. The doctors suggested cranial radiation, which Kimmo agreed to. He had made a resolution not to give up; he went to his daily appointments by public transportation and on foot. But the cancer wore him out. Soon thereafter, Kimmo collapsed and his wife called an ambulance. He was physically wrecked and mentally exhausted. Now he had been sent to hospice to gather some strength and "to get his medicines fixed" (D1: 68).

The visit to the hospice ward was a turning point for Kimmo in many ways. During our first meeting, Kimmo said that after being ill for months and meeting a number of doctors and specialists, this was the first time that he felt that the doctor actually *saw him* as a real person, as another human (D1: 62).[124] During one long night on the ward, Kimmo had an intense conversation with one of the nurses. She told me later that her job was to give him "a safe place to face his situation." From what Kimmo told me, this is exactly what had happened that night. Until then, Kimmo had held onto the thought that he could manage, that if he just tried hard enough he would be okay. He had desperately struggled to remain in control. After his

[124] It was rather common to hear patients contrasting their experiences in the hospice home with their previous encounters with medical staff.

conversation with the nurse, Kimmo started to relax and give in a bit. "I had this realization that nothing is eternal," he told me. "We all die. Maybe I'll die in six months' time or maybe I will die in only twenty years." To accept this thought was a huge thing to Kimmo. Yet, at the same time he continued to emphasize how his own efforts could make a difference. Kimmo shared that it was equally important to understand what one *can* do about it. He continued, "I *can* take care of this body of mine and I *can* eat well, but it is not *all* in my own hands" (D1: 118–119).

Over time, when I came to know Kimmo a little better, I realized that this tension was a characteristic feature of his end of life. Kimmo had two rather contradictory ways of approaching and speaking about his situation. On one hand, he was openly looking at his deteriorating physical condition and facing the painful idea of death. Paradoxically, Kimmo explained that it was actually the heavy medical treatments which had forced him to accept his situation; the second round of chemo, and especially the radiation on his head, had put him into a "really bad condition." All this, he said, had "trained" him to understand that not everything was in his hands (D1: 117–118). When Kimmo was reflecting on all this, he was teary and had a very vulnerable air about him. He was in a lot of emotional distress; he would lament, for instance, about not being able to see his children grow up. Yet, on the other hand, part of him persisted in a state of disbelief about the terminal nature of his illness. Until the very end, Kimmo kept talking about his "recovery" and "progress" of getting better (D1: 122). Later on, a nurse told me that until the very end he kept eating protein supplements and trying to recover his muscle tone in the gym. He never quite accepted the finality of his situation, and he never gave up the idea that he could somehow pull through. In hospice language, his "adaptation process" was still undone when he died.

When Kimmo looked at his horizon, perhaps he *saw* death, but he chose to look at life. Nursing scientist Mirja Sisko Anttonen refers to patients who simply refuse to handle the information about a life-threatening disease (2016: 64–65), and who consequently refuse to prepare themselves for death (2016: 99). Although for some (like Peter), the denial of the reality seemed steadfast, I would however suggest that in most cases the sentiments about the possibility of death were complex and fluctuating on a daily basis. Here Kimmo seemed to share Sartre's attitude: "I can neither discover my death nor wait for it nor adopt an attitude toward it, for it is that which is revealed as undiscoverable, that which disarms all waiting…" (Sartre 1956: 545). In this case, the only possible recourse is to look at life and to keep *moving in life*—just as movement was life for Kimmo. He continued to emphasize his physical exercise, which, at the hospice, was reduced to making laps with a walker around the ward. Later on, when he was able to return home (where he spent his final days), he continued going to a gym for rehabilitation. He also made an effort to eat healthily and well. It felt to me as if he thought that because one dies from not eating food, it must follow that one cannot die if one keeps eating. This was Kimmo's way of *doing* his own death—while death was slowly undoing him.

Dying as a project

Inkeri's manner of processing the terminal situation was quite unlike any of the others that I encountered during my ethnographic research. We met at the day hospice, and very soon thereafter it became apparent how she was persistently seeking to understand what was happening to her by studying her situation, both in regard to its medical frame but also philosophically. For Inkeri, philosophy was entangled with art and sensorial creativity, and thus for her, doing art and crafts was a philosophical process. As I will discuss in more detail in Chapter 10, creating art was her way of facing death.

Aside from having a long professional career elsewhere, Inkeri was also an artist who had studied psychoanalysis, which was formative to her life philosophy. After Inkeri heard about my research, she became very interested in it. During our first actual interview at the hospice home, she admitted that my being there made a real difference for her: "Most important to me was to get to know the staff and the atmosphere here, and then this thing of yours was, of course, extremely interesting. This awoke a huge inspiration in me, that I got this possibility to be encountered via [sharing] one's own story, which is exceptional…" (Inkeri/1).

In our first interview, Inkeri told me that she had learned about her illness a few years before, after suffering from different kinds of symptoms for some time. The lung polyclinic finally gave her the bad news: strong suspicion of a malignant tumor in the chest area. "When I left for home in some sort of shock," Inkeri recalled, "I thought that I need to start writing about this now, so that I can get through this, even though I am not really a writing type, as I've always expressed myself via other media." At that moment, however, Inkeri felt compelled to process her situation by writing. On the way home, she went to a bookstore, where it took her "probably an hour to choose the right notebook." She continued:

> When I got home, I certainly did not start writing right away, but it took me about three months to figure out how I wanted to cover the notebook! It was its own process. Finally I was able to cover the notebook, and I gave it a name, and I have it even now with me, as I thought that maybe here I could write in it… (Inkeri/1)

At this point in our discussion, Inkeri started to search for the notebook in her bag, in order to show it to me. The name given to the notebook was actually a sentence that had come out of her grandchild's mouth upon seeing her sick for the first time. After the initial diagnostic operation, she had a large bandage on her chest where they had performed an endoscopy, and the four-year-old had looked at the bandage and then exclaimed, "It's good that there is no bone showing through, since one could even die from it!" The name of the notebook was "Since one could even die from it" (Inkeri/1).[125]

This story illuminates Inkeri's manner of living—and dying. When she learned about her terminal condition, it quite naturally shocked her, but immediately she felt like she needed to

[125] Later on, about two weeks before she died, Inkeri sent me her notebook. She wished me to use it in my research. The notebook was not a diary. It was more like a piece of art, Inkeri's last artwork made for this world.

process the situation in some tangible manner. In the past, she had always done sculpture to deal with difficult issues in her life. Material and kinesthetic artwork as methods to process were her thing. Once she began feeling ill, she had no energy to do sculpture anymore, and so she thought that she would turn to writing. However, after the notebook was covered and named—becoming in this way visually and tactilely pleasing to Inkeri—it took four years before she was able to actually start. (Inkeri/1.)

The following years were filled with fluctuating periods of better times when Inkeri was able to work in a quasi-normal way and then worse times when she felt sick and was undergoing various medical treatments. She had a pneumonectomy (lung removal), and then various chemotherapies and other targeted therapies. This led to sick leaves and an early retirement. Inkeri said that she had a "complete incapacity" or "unwillingness" to write, until one summer she attended a writing retreat with the theme "Write yourself an island":

> We studied different sorts of mind maps there, and […] when the form [as the physical structure of the writing] became clear for me during the course, the island—or rather, in my case, an interior palace, a sort of building—then I was able to get the form out, and the content was already included. (Inkeri/1)

Intuitively Inkeri drew the palace on the front page of the notebook and then gave each room its own name—those became the themes she needed to process before her death. In this way, after creating some concrete shapes for the words, she was able to see what she needed to write. She realized that the completely blank pages had been impossible for her to fill in; they were too empty, "too chaotic to grasp onto anything," she said.

I found this to be an interesting image, since I had learned from my ethnography that receiving the terminal diagnosis could result in a chaotic space in which all the previous landmarks seem to vanish. If there was nothing familiar to orient to in this new landscape of threatening death, one's intentionality could become shattered and disrupted. As Inkeri described it, there was nothing to grasp onto. Here, the notebook itself became something tangible, and its structure with titled "rooms" enabled Inkeri to create some order in her situation; it made it possible for her to orient in the new landscape of approaching death. Now she started slowly to fill the different rooms with lists of words, ideas, memories, and thoughts.

The appearance of death on the horizon dramatically changed the landscape of life, causing various negative emotions—Spinozian *sadness*—in the research participants. Sadness is always a passive emotion in Spinoza's system, that is, "anything which follows in a person where that person is an 'inadequate' or partial cause of the thing" (LeBuffe 2015). Passive affects, such as the fear and depression caused by sickness and the awareness of the seriousness of the prognosis, diminished the patients' power to act in the world. Yet some patients were able to empower themselves in the new situation by applying creative methods and doing what was in their power to do. Peter sought to empower himself with material accessories, and Kimmo chose healthy food and physical exercise. Eeva sewed her death shirt and made other preparations,

whereas Inkeri worked patiently at creating an understanding of her end of life. In this way, they all assumed active roles in being a dying patient. Inkeri made it explicit even to the medical staff that she was an *agent*, not a passive object of their medical activities. She told me that she had phoned, written, and contacted her medical caregivers: "I have willpower, and I express my will that I am a *subject* [Finnish: *subjekti*]… I always express my will to the doctors, clearly but not aggressively" (Inkeri/1). Unlike Eeva, Inkeri was not submissive. As she said herself, she really wanted to live, almost forcefully, yet at the same time she sought understanding and a resolution of some sort.

The difference between these various sorts of activities was that some of them were clearly aimed at striving for life and surviving the cancer (sports, enhancing the physical appearance, further life prolonging medical regimens), whereas others were aimed more directly toward actual death and dying (the death shirt, the notebook). For Inkeri and Eeva, these activities and efforts, which they made toward the acceptance of death, seemed to bring them some satisfaction. This could be understood in relation to Spinozian joy, since these activities empowered them to encounter death *on their terms*. I will return to these personal forms of ritualization in Part IV.

However, before going into more detailed analysis of the personal rituals, I wish to draw attention to the issue of the place of care and dying, since as I have argued, the environment was constitutive of one's experiences.

6. PLACES AND NEGOTIATIONS OF CARE

6.1 Places of care

Space, movement, and soundscape

> What upsets me is that moving has become so difficult… Would that I could go out to see some beautiful nature, or park, flowers, or something like that. Then I could withdraw for a moment from the illness. (Vivian/1)

> I always wanted to leave with my boots on, feet straight. [I am] so self-directed, stubborn as a devil… I definitely don't want to be a package that is tossed and turned around in bed. (Aili/1)

> I have been so tired, I am really tired… I start being tired of this dying, since one cannot go and do anything. It is terrible to fight against one's nature [which would want to go and do things]. This powerlessness and helplessness is terrible. (Aili D4: 30)

One of the most frequent topics of conversation with the patients concerned diminished mobility. Due to pain, dizziness, and/or lack of strength, a patient could no longer leave the house (or the hospice ward), or it became extremely challenging. This brought a new set of limitations in the form of diminished independence. Furthermore, increased inability to continue one's usual daily activities added to the uncertainty of one's future, which caused lots of frustration, boredom, and tiredness. These issues, which were talked about very often in the day hospice group, reminded me of Tuan's perspective on space. In his phenomenologically inspired writings, Tuan equates *space* with freedom and movement, with a kinesthetic experience of having room to move (Tuan [1977] 2001: 12). In regard to *place*, Tuan ([1977] 2001: 6) writes, "What begins as undifferentiated space becomes place as we get to know it better and endow it with value." Place is always something experienced and given meaning: "Place is security, space is freedom: we are attached to the one and long for the other" (Tuan [1977] 2001: 3).[126]

The sense of space changes throughout the illness trajectory. It is a commonly shared understanding in the hospice world that as a patient's condition deteriorates and they get closer to death, the life circle diminishes in both a very concrete but also more abstract sense. First, sickness limits one's mobility, preventing travel abroad, for instance, or going on hikes or walks, swimming, using a bicycle, driving a car (often because of pain medication), and so forth. How strongly a patient reacts to these changes and new limitations may depend on their previous lifestyle and personality. The further that illness develops and the more that one's physical condition worsens, the more that mobility tends to get restricted. Toward the end, one may cease to go outside or go upstairs at home, for example. Slowly, the life circle may shrink to one's bedroom, and eventually to one's bed.

[126] Tuan ([1977] 2001: 6) continues, "Furthermore, if we think of space as that which allows movement, then place is pause; each pause in movement makes it possible for location to be transformed into place." This captures the idea of space and place in a fascinating way: life is about movement in space, whereas death freezes us in place.

Of course, not all sickness trajectories go like this. There are often fluctuations between better and worse phases, and mobility once lost may come back after improving. Some of my research patients fiercely resisted their deterioration and the restrictions in their mobility, even making larger trips toward the very end of their lives. One traveled several times during her last months to an Orthodox monastery that organizes retreats in Northern Karelia, more than 400 km from her home. Kimmo insisted on keeping mobile even when he was very ill; as previously mentioned, he would make laps with his walker when he was at the hospice ward, and after he left he started going on walks outside despite being very ill (D1: 68, 109). Siru, a research patient from the day hospice, went for a holiday trip to Southern Europe, even though her condition was very frail. And Marjo-Riitta traveled to the United States to see her family just a couple months prior to her death (Marjo-Riitta/1).

Movement is easy to equate with life, both symbolically and concretely, whereas stillness and quiet remind of death. In Finland, a still winter landscape with frozen trees is traditionally associated with it.[127] "There is a deathly silence" (*on kuolemanhiljaista*) is a Finnish saying, which indicates a very quiet moment or place. Historian Outi Ampuja (2014: 263), who has done research on Finnish soundscapes and writings by the Finnish public on experiences of silence, mentions a text in which the author states that witnessing the death of a loved one was the quietest moment in their life. Usually, stillness and quiet are experienced in a positive manner, and especially when related to nature places like forest, silence is not considered threatening or scary but consoling, soothing, and peaceful (Ampuja 2014: 260–265, 269–270). My findings mirrored this perception. Research participants such as Kimmo, Matti, and Aili talked about the "peace and quiet" of nature as something wonderful. In order to stress this, Aili brought me one of her favorite poems (D1: 103). *Kysy hiljaisuudelta itseäsi* ("Ask from the silence about yourself"), by the beloved Finnish poet Helena Anhava (1983), reads at the end of the poem:

Paljoa et tarvitse:	You don't need a lot:
hiljaisuuden, luonnon, lähimmäiset,	Silence, nature, loved ones,
järjestys on tämä	this is the order
jotta luopuminen helpottuisi	so that giving up would be easier.[128]

Although often considered a mere myth, an appreciative attitude toward silence is indeed a salient feature in Finnish culture (Ampuja 2014: 264). After all, evaluations of auditory or visual experiences are always culturally interpreted (Hartig et al. 2011).

My research participants also recognized a distressing kind of silence. It might be that this feeling of distress had its roots in the intuitive association of silence with death (see also Lämsä 2013: 55–56). The quiet experienced on the ward or at home during the hour of the wolf was the worst. The silence that abides at night on the hospice ward presented a horrifying experience

[127] For instance, old Finnish folk songs as well as poetry make a symbolic equation between death and winter (see, e.g., Aaro Hellaakoski's poem *Talven tuomiolla* and Eino Leino's *Talvilaulu*).
[128] The English translation is mine. Anhava's poetry has not been translated into English.

to Peter, and others also commented on the stillness of the ward in a similar way. I heard both patients and nurses saying that in general, nighttime was an especially difficult time on the ward, and sometimes patients were scared to fall asleep at night because of the fear of not ever waking up again (D1: 137; see also Utriainen 1999: 202). Marjo-Riitta wrote in her blog:

> Sleeplessness is my new companion. During the night, I just simply don't dare to close my eyes. And even if I fall asleep for a short moment, I soon wake up to this choking sensation. What is choking me? Is it something that has to do with the illness and the state of my lungs? Or is it pure fear and grief? In the evening when I go to sleep, all my dear people come next to me. How could I ever close my eyes if there is even the slightest chance that I will not see them ever again? I want to look look look.[129] (Marjo-Riitta, blog post, 6/13/2013)

Just a day prior to his death at the hospice, Oiva had noticed that he was falling asleep even while eating, and this had terrified him. He had told the nurse that he felt he needed to watch himself every moment, just in case he would accidentally die. (D11: 129.)

Heidi did not find the silence particularly scary, but it was powerful for her and somewhat difficult to get used to. She had always had children around her, and now "you get here [the hospice ward] and stay here without anybody, accompanied by one's own thoughts alone" (Heidi/2). Silence was intimidating but also somehow fascinating to her. She described to me how she could feel kinesthetically, through her bed, the various electronic devices switching on and off around the hospice home, and by putting her head on the pillow she could feel the electric currents in the house. Within the midst of the silence, she could also hear some beautiful music in the evenings and early mornings. Her roommate asked her if she was sure that the music had been real. Heidi thought it had been, although now when she was talking about it with me, she was not completely sure anymore. In any case, it created an extraordinary soundscape. "The music is…" Here Heidi was struggling to find the correct word to describe her experience (since the metastasis in her brain had spread, finding words had become increasingly difficult for her). "The music thing is quite a… big part of this whole thing… that kind of… rather *essential*, you probably know what I mean," she added, nodding. Later on, she referred to this part of our conversation as the "spiritual talk." Thus, I concluded that even if she was not able to elaborate on the meaning of the experience of the "beautiful music," it had been significant to her—and even existentially meaningful. Heidi's description shows how she experienced that her being was materially mediated on the ward; in the silence she could listen to it through her mattress and pillow, while the music, whether it was real or not, was "essential" and even "spiritual" for her. (Heidi/2.)[130]

[129] "Unettomuudesta on tullut uusi kumppanini. Yö on aikaa jolloin en vain uskalla laittaa silmiäni kiinni. Ja jos hetkellisesti nukahdankin, herään välittömästi kuristavaan tunteeseen. Mikä minua kuristaa? Onko se jotain sairauteen ja keuhkojeni tilaan liittyvää? Vai onko se puhdasta pelkoa ja surua? Illalla nukkumaan käydessäni mieleeni ja viereeni tulevat kaikki minulle rakkaat ihmiset. Miten voisinkaan laittaa silmiäni kiinni jos on pieninkin mahdollisuus etten näe heitä enää ikinä. Haluan katsoa katsoa katsoa."

[130] There has traditionally been a connection between quiet and spirituality; in silence one can hear God better (Gothóni & Gothóni 2014).

In a demonstrable manner, the spatial, sensory, and kinesthetic memories and experiences happening in the place of care were very concrete, and thus strongly affective for patients. At the same time, the real and unreal, memory and the present, can become entangled and inseparable, and the environment can either be consoling or threatening to patients. Overall, experiences of spatiality, linked with aspects of mobility and soundscapes, were essential parts of the patients' relational embedded being in their various locations of care.

Day hospice: "On Tuesdays I have no cancer"

Day hospice proved to be a very meaningful place for many of my research patients. In the midst of the medical contexts and spaces where the patients needed to be, the day hospice—like any other location where the patients spent time regularly—became a *place* endowed with meaning. Even though they represented quite a range of people in terms of age, social background, education, and gender, the patients in the Tuesday crew grew close, forming loose but meaningful friendships by sharing intimate time together. This became especially evident at those moments when the group members learned that one of them had died. Patients also participated in caring for each other with small gestures: one might help another move around or remind someone to make an important phone call or take their medicine. Some of the group members were also in touch with each other outside of the hospice home, creating crossover between the different domains. For example, when the research patient Rauha was moved from home care (and day hospice) to the actual hospice ward, it became a custom to go and greet her in her room, and if she was well enough she would come to the day hospice room to greet her "Tuesday buddies."

For many of the research participants, day hospice was their first contact with the hospice world. The nurses told me that many patients at first felt terrified upon receiving their referral to day hospice. According to a nurse with a long career in hospice work, many react negatively in the beginning, thinking that hospice is a gloomy place filled with grieving people, but once they actually arrive at the hospice home they get a positive surprise (D2: 61). This claim was reiterated by many of my research participants. After the initial shock of getting a referral to a hospice, many came to think that it was actually a rather "wonderful place" (D1: 6; D2: 61). Every now and then, there was a general discussion among the Tuesday crew on how and why the hospice was such a "wonderful" place. One of the patients said that the hospice home was "the safest place to come to," and another added that "it is so relaxed here, one can be just oneself" (D4: 19). When I talked about this with Inkeri, she noted that the group spent five hours together each time. It was longer than any other (peer) support group she had ever attended. According to Inkeri, the atmosphere was respectful but permissive; there were no obligations to do or not do something, nor were there any forceful discussion circles where people needed to answer or say something. One could participate or not, and the atmosphere was free and appreciative, Inkeri explained (D4: 19). In reality, the day hospice was also an

institutional space striated by regulative practices, so that being there, as we shall see, was not perhaps in the end as "free" as was often talked about.

The day hospice was also a place to socialize for those who lived alone or whose mobility was limited, and simultaneously it offered a break to their caregivers at home. Aili, who greatly enjoyed the socializing aspect, summarized her sentiments about hospice by stating, "On Tuesdays I have no cancer!" (D2:61). During day hospice, she could forget about the possible anxieties related to her illness; it was a social moment that enriched her daily life, she explained to me. Furthermore, it was common to hear patients and especially staff talking about the day hospice—and the hospice home at large—as a place for "ordinary living and sharing," not so much for dying. This sort of discourse reiterates the common hospice ethos shared by hospices around the world, yet it also actively constructs a certain kind of affective frame, or ideal, for the dying.[131]

There were naturally other kinds of sentiments about the hospice as well. Hospice homes make ambivalent spaces, where individuals constantly negotiate living and dying—and the paradoxical everydayness and uniqueness of the end of life (Worpole 2010). For some patients, such as Peter in the last chapter, the continuous reminder of the coming death encountered via other patients; the constant "living the end" caused anxiety and even disgust. Peter also seemed somewhat annoyed by the ongoing pampering by the (female) nurses (D4: 11). The hospice home is a gendered place where almost all the staff is female. Utriainen, who studied a hospice home two decades ago, mentions how male patients appreciated a male nurse by their side, both in terms of physical care and otherwise (Utrainen 1999: 217). These ambivalences also become visible in the spatial solutions made inside and outside of the hospice building, such as, for instance, its entrances and exits which seek to separate the living and dying (Verdeber & Refuerzo 2006; Worpole 2010). At its best, however, hospice indeed appeared as a kind of "safe haven" that some patients referred to, a place of repose (Tuan [1977] 2001) in the midst of the open-ended space of living and dying.

Where to die?

An important part of advanced care planning (ACP) is the discussion where the care will physically and concretely take place and, eventually, where the patient wishes to die. According to international research on the topic, most people wish to die at home, yet some prefer institutional locations such as care homes or hospitals—possibly because they live alone or they might fear of being a burden to their families (Beccaro et al. 2006; Aaltonen et al. 2010; Anttonen 2016: 95). According to a study from 2010, the most frequent place for Finns above 75 years old to die was a municipal health center (48%); after that, the second-most common place was a general hospital (19%), while a private home was only in third place (16%) (Aaltonen et al. 2010).

[131] If one browses the internet for information on hospices around the world, one finds websites using the following slogans: "Hospice is about living fully," "Hospice is about living not dying," and "Hospice is a respect for life."

According to reports by the Ministry of Social Affairs and Health, about 3,000 patients were in hospice care in 2012 (just prior to the time of my fieldwork), while the need for care was for 12,000–13,000 patients.[132] This means that in 2012, about 9,000 patients in need of specialized (demanding) hospice care were cared for within units of specialized medicine or primary healthcare (ETENE 2012: 56). These places may lack knowhow of palliative medicine; moreover, these units are architectonically designed for curing and surviving, not dying or the care of the dying. This affects the way in which care can be carried out, as well as the way in which it is experienced.

In regard to their wishes about their place of death, many of my research patients opted to die on the hospice ward rather than at home, even though the latter was an option provided by the hospice team. Sometimes a patient wished to die at home, but when they were closer to the actual moment, due to various reasons such as a general feeling of not being able to cope with the situation, they chose instead to go to the hospice home. The way in which my research participants talked about this revealed their deep feelings of trust toward the hospice home as a place. This seemed to be the most significant factor affecting the decision. The professional atmosphere gave patients the impression that it was possible to die peacefully in hospice without pain (even if that was not always actually possible), and this sense of security created a sense of existential safety. Many patients talked about being grateful about the possibility to die in the hospice home. One family member told me that she was so happy to be able to tell her mom that she had got a place there: "My mom's eyes lit up and she was so relieved" (D1: 54).

What seemed to affect patients' wishes in relation to their final care location was the way in which they pictured themselves in relation to their family members. Echoing earlier research (Johnson et al. 2007), some of the participants verbalized fear of being a burden to their loved ones. I also heard comments about how patients themselves felt stressed about needing to perform well and cheer up before the eyes of their loved ones (Heidi D1: 103; Kimmo D1:73, 117). Heidi was anxious because of the affective misalignment; she felt that her youngest child assumed that she was "just like before," whereas Heidi herself knew that her condition was nothing like that (Heidi/2). She suffered due to knowing that she could not perform in the eyes of her children in the way she wanted to. At the end, Heidi was practically paralyzed and her symptoms were rather difficult to manage at home. According to her wishes, she died in hospice with her family close to her.

Thus, the issue of place can relate to the way in which the dying person wishes to "perform" or "picture" their end of life. Losing control over one's own body was a terrifying thought. The existence—or even the possibility—of challenging symptoms, such as breathing difficulties and unmanageable pain, scared and worried them. Many were anxious about the actual *moment of dying*, and equally many told me that the hospice had guaranteed to ease their pains, even

[132] Due to the recent progress in palliative care in Finland, the situation has improved in many regards since 2012 (Saarto & Finne-Soveri 2019).

promising palliative sedation in the case of extremely difficult symptoms. In this way, hospice was seen as a place that supported a safe and dignified manner of dying—including situations where one had fear about "losing it."

The imagery of a heroic manner of facing illness and death was something that was criticized by some. The last time I saw Vivian at the hospice ward, we talked about the difficulty of dying. At the time of our meeting, she was very close to death and she openly talked about her fears. She told me about a memorial she had read, and described how it had praised the deceased for having been so strong and perseverant, meeting their destiny without complaining. Vivian got upset and annoyed by this. She felt that this way of talking about and picturing dying transformed it into another performance that individuals needed to go through in a certain way—in a *correct* way—in order to not die "wrong." Reflecting on her own manner of dying, Vivian said that unlike the "brave ones," she had for sure complained. She continued to think and then remarked that "there cannot be a right or wrong way of dying" (D4: 28). For a moment, we also talked about the "warrior talk" so typical of cancer patients, and how Vivian disliked it.[133] Vivian was open and verbal about her feelings around the difficulty of dying, but also how the hospice home offered her the kind of place where she was able to do it in her way, without any need to perform in a certain manner.

In regard to the issue of place, Kimmo was worried that his children might feel embarrassed of him. His anxiety was related to his physical appearance, about which he felt rather disturbed (D1: 72–74). As noted above, Kimmo was accustomed to live very physically, first when growing up on a farm where work was part of everyday life and then later on when he kept himself physically fit through various sports (D1: 72). When I met him on the hospice ward, he was wondering if his experience of losing strength and control of his body was similar to what his mother had experienced during the end of her life. In her final years she had had a very difficult hip fracture and she wasted away slowly (D1: 73–74). His reflections are congruent with the idea of earlier experiences in relation to death affecting the way in which patients see and interpret their own situation.

Kimmo fought against physical fragility, and he was determined to be rehabilitated. As explained above, he made efforts to remain as independent as possible when he left the ward and returned home; to support this, he took long walks and went to the gym (D1: 91). However, as Heidi stated, home represented the "normal life," whereas hospice, even though it supported feeling safe and secure, was ultimately about illness and death (D1: 103)—and, in the end, not so much about "the normal everyday life" that the slogans advertise. This was a keen difference between the perception of those who only came for the day hospice meetings and those who had been admitted to the ward. On the ward, the institutional side of the hospice became actual. Kimmo was very aware of this. He became moved when he observed that unlike on the hospice

[133] It is well known that with illnesses in general, and perhaps especially in the case of cancer, there is a tendency to apply rhetoric of war in regard to the disease. Since Susan Sontag's *Illness as Metaphor* (1978), many studies have been done on this theme.

ward, at home one could tangibly touch and be touched by one's loved ones (D1: 73). We never talked about his desired place of dying, and I got the impression that Kimmo had not really thought about it either, for he was still keen on getting better. Kimmo ended up dying in an emergency room after collapsing on his way home from the gym.

Pekka, a man in his fifties whom I met on the cancer ward, was given less than six months to live after his cancer operation proved to be unsuccessful. Nevertheless, according to him, he had never talked about his possible place of dying with his wife or with a doctor.[134] When I talked with Pekka and his wife about hospice care, they told me that they had not thought about "these kinds of things" but took it "one day at a time" (Pekka/2). A couple months later, as Pekka's condition worsened, he made up his mind that he wanted to die at home. Pekka's wife later shared with me that this decision had partially been made because Pekka deeply hated hospitals, but also because he wanted to die close to his dog. Pekka was worried that if he went to the hospital to die and just disappeared from the dog's life, the dog would feel abandoned. His wife told me that Pekka firmly believed that the dog would understand his leaving by witnessing his death. In the end, Pekka died at home. (D4: 32–33.)

Helena died in a small municipal healthcare center. She had a private room where her family could gather, and the palliative team from the nearby university hospital assisted in her care, especially in regard to the medication, she explained to me. According to Helena, this was the best possible place for her in regard to the location and her family—the healthcare center was close to her home, where her children were. The surroundings in the healthcare center were not ideal for dying, however. The ward was aimed at rehabilitation and its spaces and activities were designed accordingly. Helena's room was next to the ward's living room. On the other side of the thin wall was a TV with the volume turned up high for the old people who comprised the main patient group on the ward. She complained that the TV was turned on in the morning and left on until late evening. Helena spent more than two months on the ward before she died. (D3: 87.)

The issue of care places and locations of death is connected to the question of the *type* of care that patients received. Different places offer different kinds of treatments but also care with different aims: curative, disease-modifying, or palliative care. Thus, the patients often became familiar with various medical sites during their illness trajectories. Accordingly, there were multiple moments when the patients needed to hear, talk, and negotiate about their care not only with medical staff but also with their family members, and perhaps even with themselves, in order to better understand their situation and make better decisions concerning the end of life.

[134] While I cannot know for certain that this was indeed the case, the most important point here is that this was Pekka's understanding of the situation.

6.2 Negotiations of care

Negotiations around care

Talking about the end of life or end-of-life care was not easy for the patients. However, many of my research participants did want to discuss their *previous experiences and encounters* within the various medical contexts and places where they had been. It gave me the impression that some of these meetings had been onerous, even to the extent that they had colored the patients' whole end-of-life experience. This interpretation is supported by previous research, according to which prior experiences with healthcare affect the patient's current abilities to deal with their situation or their prognosis (Schaepe 2011). Especially the moment of receiving the bad news—or, rather, the *process* involved that—has been found to constitute a "key part of their illness journey and remembered as significant" (Matthew et al. 2019: 2291).

Kimmo spoke a lot about the communication difficulties he had had with some of his doctors, and he claimed that the patient has to demand proper information about their condition (D1: 121–122). Kimmo explained that as long as the conversation was centered on an X-ray picture, for instance, he was given a very detailed analysis of the tumor, but as soon as he asked about the practical implications of all of it, the conversation was swiftly concluded. Giving another example, Kimmo said that he received proper instructions from his physician on how to treat the allergic pimples he got from his cancer medicine, but there was never any actual talk about the advanced cancer itself. Kimmo argued that before arriving at the hospice, he had never had a decent conversation with a doctor about his terminal condition. Kimmo's experience was probably the reason why he told me that if there was anything that my study could convey to medical staff, it was that patients should be given a matter-of-fact explanation about their situation and about the possible course of the disease, including its likely prognosis. This would make it possible for patients to understand what is happening and to make some crucial decisions toward the end of their life. (D1: 121–122.)

Conversely, Helena felt that there was an abundance of information given to her:

> In the visit, the doctor told in a very detailed manner about the tumor, and what kind of a tumor it was—in a very scientific manner—that the tumor was this and that kind. The results were not very good for me. They gave me this list, in which there is *t* for tumor and *g* for grade and *m* for metastasis, and the classification goes from one to three. […] It was three for the tumor; it was big. The grade was three; that is about how fast it can grow. The only one that was zero at that point was the metastasis. It did not feel very good, one's own diagnosis. I had read maybe even a bit too much about those [numbers] at that point, online, I mean. It was very mechanical. The medical results were brought in, and there were no questions asked about how I felt or how I was doing… (Helena /1)

The medical treatment was also explained in great detail:

> [Then they] started to look at the computer, saying that "since you have this and that kind of a tumor, it means that…" And they started to explain that "you will be receiving this and that kind of chemotherapy," and they explained it very carefully by using all the names of the medicines and telling that "this influences this way" and… Like, using the medical language.

> Well, in their own opinion, they probably did great as doctors, since they were explaining everything with such care. I guess everybody would not have explained it so well… But of course there was no connecting with the person at all. It was just about the quality of the cells and so forth. But we humans are all so different. I know many [patients] who really want to know all these details very exactly. (Helena/1)

As Helena points out, people make different kinds of patients, and some benefit considerably from a very detailed scientific medical explanation of their condition. What Helena herself seemed to miss at the consultation was not medical information but an empathetic encounter with the doctor. However, a little later on in our interview, she admitted that she was the kind of person who would not have started to open up at the consultation, and that she was not even expecting the doctor to have the kind of time to think of the overall wellbeing of the person. (Helena/1.) While the expectations and experiences that patients had in regard to their medical encounters varied, many research participants agreed that doctors did a great job at explaining medical details to their patients. What that information implied in practice, or what it may have meant to one's life, was more unclear.

Simultaneously, it can be a challenging moment for a doctor to share their prognosis assessment with patients, and some may seek to avoid it (Lamont & Christakis 2001; Hietanen 2015a, 2015b; Fenton et al. 2018). Perhaps because of this, instead of speaking about the actual disease and reflecting on what it might mean for the patient, physicians may at times focus on medical interventions and treatment details (Henselmans, Laarhoven et al. 2017). If it is difficult for a physician to enter into a discussion on ending disease-modifying treatment, it is even harder to conduct that discussion in such a manner that the patient actually comprehends it in the way intended by the physician (Hietanen 2016). As in the case of Vivian, receiving the diagnosis can cause such a shock that one cannot hear, think, or act straight.

Kimmo's requests to hear the prognosis early on echoes recent recommendations for physicians to bring up the prognosis and speak about it early enough to integrate palliative care as part of the care plan (Current Care Guidelines 2019). In this way, the patient also has time to think of their priorities and wishes for end-of-life care (Henselmans, Smets et al. 2017). Perhaps the best way to ensure successful communication is the cultivation of *trust* within the relationship of doctor and patient (Heyland et al. 2006). For this, there needs to be an existing relationship to start with—that is, an ongoing doctor-patient relationship. As it stands now in Finland, the system of teaching hospitals engenders care relationships that are constantly changing, as patients meet different doctors who are rotating through specialization periods. This results in an environment where it can be challenging to develop a trusted connection with mutual understanding (Hietanen 2016).

Patients and their family members suffered from this endlessly changing cycle of doctors during their care (D2: 91–92). Kalle Holmberg (2015), a well-known and much-loved Finnish movie director and cultural persona, talked about this in his presentation at a hospice seminar.[135]

[135] The *Hyvä kuolema on jokaisen oikeus* seminar was arranged in Helsinki in autumn 2015.

His wife had died a year earlier, and Holmberg noted that during her last months she not only met with but was in the actual care of fifteen different doctors. Some of my research patients, such as Vivian and Inkeri, had resolved this problem by finding a "trusted doctor." For Vivian, this was her former occupational physician, whereas Inkeri found solace in her old family doctor. Just like Holmberg's wife, Inkeri met with numerous different doctors while undergoing tests with more and more findings, especially in the beginning of her illness trajectory. This all felt "chaotic" and "terrifying" for her. She was in shock, unable to understand what was really happening. Finally, her husband told her to go to meet their family doctor, whom they had known for decades. Even though a general practitioner has no particular knowledge about specific terminal diseases, both Vivian and Inkeri kept going back to their doctors at different points in their illness trajectories in order to gain a fuller understanding of the situation, as they put it. For both women, these meetings provided great consolation. They felt as if they were being fully heard and seen as humans. Inkeri told me about one meeting with her old doctor: "I vividly remember that empowering feeling when he said to me, 'This is a challenging situation but we can manage this. The battle shall begin. I'll be there with you!'" (Inkeri/1). Inkeri told me that she usually avoided the typical cancer rhetoric of war and battle, yet here, on this occasion, it felt appropriate.

> He really took my case as his concern. Until then, all of the testing had been so erratic, with so many different doctors. Of course, I understand that this is the system, but when I received his words… they were just earthshaking… It helped me mentally. I always wanted to emphasize the issue of *trust*, that there needs to be trust, that otherwise one cannot make it through this. For a while, I was visiting this cancer support group where I heard horrific stories about people's encounters with their physicians. I needed to protect myself from that. (Inkeri/1)

It is important to note that even when a patient is receiving obstructive or palliative treatments (such as pain-relieving radiation therapy), they do not necessarily understand (or want to think about) the palliative nature of the care and the aims of those treatments.[136] Some patients do not understand their terminal condition, even though physicians explicitly emphasize the prognosis and carefully explain the situation to them (Gramling et al. 2016; Robinson & Jagsi 2016). In general, according to the studies, patients tend to have a more optimistic understanding of the situation than their physicians do (Gramling et al. 2016; Robinson & Jagsi 2016). My ethnography suggests a similar discrepancy in the way that some research subjects viewed their prognosis; in particular, they talked about their palliative treatments as if they believed they were getting better—or that they would ultimately even become cured—due to them.

[136] According to a study conducted in the United States (Weeks et al. 2012), a majority of patients (75%) with advanced metastatic cancer receiving palliative chemotherapy believed that the treatment was curative. This does not necessarily correlate with Finland, however, where physicians are encouraged to tell about the incurability of the cancer when applicable. This must be widely practiced, since some patients have even complained about this "constant need to remind" about their condition (Saarto 2020, personal communication).

At the same time, some patients keep receiving aggressive treatments until the last weeks of their life. While there are somewhat conflicting ideas about why this might be the case, one possible perspective became clear when discussing it with a senior oncologist (see also Tarkkanen et al. 2020). As it stands in Finnish law (Act on the Status and Rights of Patients 785/1992, §5–6), a patient must be informed about all possible and available treatment options, and the decision about the commencement of any care should be made with mutual understanding. This means that, in practice, when curative treatments are discontinued, the doctor will discuss the remaining treatment options with their patient. If the disease is very advanced, it may not be reasonable to proceed with aggressive or invasive treatments, even if they could extend the patient's remaining time for some weeks or months. This makes sense from the doctor's point of view, as they are familiar with the possible side effects, which can be rough and can fill the remaining time with unnecessary suffering. However, even if this is what doctors might want to recommend, they nevertheless also have to present the other options to the patient. In the experience of the oncologist with whom I talked about this, it is almost impossible for a patient *not* to opt for a medical treatment if one is available. Patients, as well as their family members, feel like they *ought to do something*. Given a lack of anything other to do (such as religious rituals), they choose to *do medicine*. Also, patients may pressure physicians by saying, "There must be something you can do about it, right? A new medication to try? You don't suppose that I would just sit and wait for my death!"

When Marja-Liisa Laakkonen (2005) studied Advance Care Planning among elderly terminally ill in Finland, she had a similar finding: many elderly patients wished to pursue life-saving treatments, including aggressive forms, even when their prognosis was terminal. Many of my research participants (such as Inkeri, Vivian, Peter, Siru, and Helena) also wanted to continue aggressive treatments and were willing to try anything that would give them more time. In this way, cancer treatments and drugs can become a source of existential hope (Tarkkanen et al. 2020).

Smooth and striated in the care of palliative patients

One way to understand the dynamics in palliative and hospice care is to look at them from a Deleuzoguattarian conceptual of the smooth and the striated.[137] The importance of concrete emplacement for Deleuze and Guattari comes from their conviction that "*where something is situated* has everything to do with *how it is structured*" (Casey 2013: 357). For example, in regard to voyaging (which Deleuze and Guattari associate with thinking),[138] they conclude that

[137] The concepts of "striated" and "smooth" go back to the French composer Pierre Boulez, who contrasted striated musical forms, such as those based on fixed schemata (e.g., the octave), and smooth forms, which allowed irregularity in terms of scales (Deleuze & Guattari 2016: 555; Casey 2013: 357). In *A Thousand Plateaus* (2016), striated and smooth are discussed not only in relation to space but also technology, maritime reality, music, mathematics, physics, and aesthetics. The contrast between striated and smooth space coincides with some other distinctions that Deleuze & Guattari draw, such as between the nomadic and the sedentary, nomadic science and royal science, and the political and politics (Walsh 2012: 55; Lysen & Pisters 2012).

[138] For Deleuze and Guattari, thought and thinking are active and affective ingredients of life (Walsh 2012a: 59).

instead of being about quantity of movement, the difference between voyaging smoothly or in a striated way is about "the mode of spatialization, the manner of being in space, of being for space" (Deleuze & Guattari 2013: 561).

In regard to care, biomedical practices can be seen as attempts to *striate space* (Deleuze & Guattari 2016: 424–436), that is, to create predicable structures and processes within the chaotic smooth space of embodied illnesses (Walsh 2012a, 2012b). In striated space, such as at hospitals and clinics in Finland, trajectories of movement are subordinated to points within space; that is to say, the patient moves from one point (e.g., doctor, treatment) to another. In smooth space, such as in hospice or elder care, the points tend to be subordinated to the trajectory of the patient (Casey 2013: 358; Deleuze & Guattari 2016: 556). That is, the services and treatments happen around the patient and come to the patient rather than vice versa. In this way, smooth space is intensive rather than extensive (Deleuze & Guattari 2016: 557).[139]

However, as a way of doing things or doing space, striation is never complete or completely separate from smooth, and there is constant fluctuation and transformation happening between the two (Osborne & Rose 2004; Deleuze & Guattari 2016: 552–581). Furthermore, both the striated and the smooth are understood as necessary and important; they describe different types of processes that are in constant relation to each other.[140] These sorts of dynamics can be seen as taking place in palliative care. If medicine occupies thinking in striation and a hospital is a typical place where striations of medicine are practiced, then the hospice movement—especially in its early days (see Lewis [2006] 2011: 6)—reflects an attempt to smooth the striations of the medicalized care of dying. Instead of moving from one point of treatment to another in striated medical space, the patient herself becomes the point of action; hospice is centered on the dying body, which tends to undo all organizational boundaries.

The smooth space of the dying body and the dying body in smooth space in hospice are both occupied by various kinds of intensities and affects. However, some scholars have debated that the current form of palliative medicine emphasizes symptom management and quantification (see Clark 2002; Randall & Downie 2006), thereby seeking to (re)striate the smooth of the

[139] In terms of connections between medical practices and the Deleuzoguattarian conceptualizations of smooth and striated, philosopher Brian Walsh (2012a, 2012b) has written on evidence-based medicine (EBM) as an attempt to striate both the fluid, unpredictable lived reality of patients and the encounter the doctor has with their patient. Professor Emeritus in Medical Humanities Alan Bleakley has analyzed the transition of modern medicine from an autonomous profession to a team-based inter-professional practice in terms of smooth and striated spaces within hospitals and clinics (Bleakley 2013). Yet, whereas Bleakley examines medical practices from the practitioners' perspective, I am obviously concentrating on the patients' experiences and movements within the system. Bleakley makes some interesting observations, pointing out, for instance, that various smooth spaces in the hospital, such as corridors, may offer sites for fruitful encounters in-between various actors and professionals at the hospital, and therefore they may become important catalysts for democratic collaboration. These sorts of transitional liminal places and instances are also the ones that may become affectively significant for patients.

[140] In spite of the obvious preference for the smooth mode of being in space, Deleuze and Guattari highlight the value and necessity of both. Furthermore, the two are in continuous fluctuation and their borderline is always shifting; there is no "pure smooth" or "pure striation." At the end of the chapter "1440: The Smooth and the Striated" in *A Thousand Plateaus*, Deleuze and Guattari (2016: 581) write: "Never believe that a smooth space will suffice to save us."

hospice. On the other hand, various reactions are continuously surfacing to counterbalance the medical striations in the realm of hospice. These include, for instance, the promotion of further alternative modes of care, such as touch therapy (Styrman & Torniainen 2018), and new ritualizations for the end of life and dying (Carson 2011).

In this way, it is possible to see the hospice home as a possible *smooth space within striated medicine*, which is another way of seeing the countercultural nature of hospice praxis. Yet, the issue is rather complex, as noted above. As we shall see in Chapter 8, at the level of material practices, such as eating hours, there was a constant dynamic movement in-between the striation of the smooth and the smoothing of the striated at the hospice. The same happened in regard to spatiality; through the command of a nurse or a doctor, the informal day hospice became a clinic-like space to conduct medical procedures, such as dispensing medications, checking vitals, or cleaning and caring for wounds. Alternatively, when the hospice care team entered someone's home, it transformed from a smooth space to a striated area of medical care, although in such situations the tension between the two was always present; an alteration in the mode of spatialization, in the manner of being in space, was constant.

The general development of the healthcare policies in Finland (such as opening palliative wards within hospitals), as well as some medical and technological developments, have pushed hospice into a more striated direction, whereas some other practices may simultaneously open up more smooth areas not only within the hospice space but also in hospitals.[141] One example of the technologies that increase the striation of hospice is the type of work cell phone that was used by the staff on the hospice ward. On one hand, these cell phones enabled efficient communication among the staff and this probably ameliorated the care in certain ways. On the other hand, the fact that people were constantly "on the (striated) grid"—that is, in reach of communication but also control—led to interruptions and striations in the immersive and intense moments of personal care. The senior nurse who pointed this out to me argued that in practice, this has decreased the intimate one-to-one moments with the patients (D1: 87). Yet, it was often exactly those loosely structured and informal one-on-one moments—reflecting the smooth mode of spatialization—that enabled the kinds of conversations that proved to be perhaps the most healing and therapeutic for patients' emotional and even spiritual wellbeing. Kimmo told me that an intense conversation with the night nurse (who was able to attend to his concerns at night without interruptions) had dramatically changed his understanding of his existential situation. It had greatly affected his ability to accept his situation—even if this acceptance was only momentary.

However, communication technologies like cell phones or tablets cannot simply be labeled striations, since for patients they have the power to break spatial boundaries by virtually bringing their loved ones close to them. Thus, technology can also help to smooth striations and

[141] A good example of smoothings in contemporary hospitals is the presence of various kinds of artwork, such as at the New Children's Hospital in Helsinki, which, in addition to visual art, also has an interesting and soothing soundscape created specifically for the hospital (Pohjolainen 2019).

create virtuality within the institutional care place. Equally, as we can see from the following description, elements such as massage (or touch therapy) and music therapy, which were actively practiced at the hospice home, broke the striation at moments and brought more one-on-one care and haptic experiences for patients and staff alike.

I was doing my interview with Matti at the hospice home when suddenly there was a knock on his door. Two women came in and introduced themselves as musicians: "Would you like to hear something? Any particular wishes?" Matti seemed hesitant since we were having the interview, but I encouraged him. Matti asked, "Well, would you by any chance have some Sibelius?" The women started playing a song by the Finnish composer, one on violin while the other one sang. This unexpected moment completely halted everything that was going on in the medical space around us. It was as if a new dimension opened up in the hospice room. Since the space was rather small and the music was quite vivid, we were completely immersed in the sounds of the violin and the singing. "Thank you! That was so beautiful," Matti said after they finished. "Sibelius is always Sibelius," he said with a sigh. (Matti/1; D2:109.) As we shall see in Chapter 10, such smooth interruptions in the form of aesthetics can offer the patient an entirely different—and sometimes very insightful—perspective on their situation, which usually is organized according to structures of medicalized care.

Medicalization striates care in relation to time and space by creating more controlled and more controllable micro-realities in the otherwise unpredictable process of dying. Such striation aims at universality, whereas smoothing is concerned with singularity (Deleuze & Guattari 2016: 441). Dying processes tend to be as singular and unique as the individual who is dying; indeed, a smooth mode of being would also seem to enable smoother dying. Yet, it is not so simple. First of all, there are always techniques practiced within the smooth space that aim at striation. Ritualization and rituals, for instance, can also be perceived as forms of striation. Rituals structure, organize, and systemize reality, especially in moments and places where the smooth threatens to disintegrate everything. This is the challenge of the smooth space. In its fluidity and unpredictability, "tolerating smooth space requires high tolerance of ambiguity" (Bleakley 2013). Second, in the end, both smooth and striated have their place. While it is true that the striation of space can facilitate the exercise of power, striated space itself has no inherent politics (Osborne & Rose 2004: 218). It would be easy to simply dismiss striation as something negative and repressive, and smooth with something positive and liberated, but this was not what Deleuze and Guattari meant with their conceptual division. Deleuze and Guattari (2016: 565) write, "Perhaps we must say that all *progress* is made by and in striated space but all *becoming* occurs in smooth space" (italics mine). Good palliative and hospice care *need* striated space, including its organization and the benefits received from effective biomedicine; indeed, effective pain medicine, for instance, is an essential part of the successful care of the dying.

Ultimately, dying and death are opposing forces against striations of life in the sense that they undo and decompose every bit of order and structure possible. Consequently, the actual

process of dying—the "becoming corpse" (Braidotti 2006: 40)[142]—requires a different kind of space and approach, that is, smooth space. In the dynamic process of dying, it is all *about the trajectory itself*, the constant present. From the dying person's perspective, there is only the middle, the *milieu*, the open space where one is and ceases to be. Striated and smooth presuppose each other; they both serve their purposes, and like anywhere in human life, there is surely a need for both in the realm of illness and dying as well. In conclusion, rather than analyzing and describing the dynamic changes and variations that are happening in modes and spaces of care strictly in terms of patient-centeredness on one hand and system-centeredness and objectification on the other, using the notions of smooth and striated provide more nuance and also more accurate discussion.[143] A further interesting thought in regard to hospice is that perhaps the hospice movement smooths striated medicine, while in regard to death and dying hospice itself tends to seek striation, not necessarily with the help of medicine but rather with ritualizations and rituals aimed at creating safety and order for patients' end of life.

[142] Although Braidotti's philosophy shares Heidegger's general understanding of the subject as interconnected and open-ended being, she opposes Heidegger's emphasis on death and finitude as constitutive of the subject (Braidotti 2006: 40). To take the mortality or finitude as "the trans-historical horizon for discussions of 'life'" is too narrow of a perspective for Braidotti; it is too individualistic and anthropocentric (Braidotti 2006: 39). Before and after an individual death, there is life (*zoe*) "always already there" (Braidotti 2006: 40); thus Braidotti's "becoming corpse" emphasizes the continuous and processual nature of life.

[143] This is not to say that objectification does not happen. Indeed, it surely does in certain places and moments. And yet, this is not actually dependent on the striation but can happen anywhere.

PART III – INSTITUTIONAL RITUALS AND PRACTICES

The third part of the dissertation focuses on the various institutional rituals found in the context of dying. In the beginning of the seventh chapter, I will start exploring what kinds of elements medical practices involve and what kind of effects they may have when they are studied from a ritual perspective. Subsequently, I will continue analyzing how the issues of power, agency, and the body are entangled in the research participants' experiences in regard to the medical practices, how techno-medical agency is experienced among patients, and how patients' bodies can be seen simultaneously as disciplined, dependent, and vulnerable.

In the eight chapter, I turn the analysis toward rituals and ritualizations performed in day hospice care. I will describe how seemingly small ritualizations of everyday life can make a great difference in a patient's experience vis-à-vis their (existential) situation and lifeworld, and I will show the ways in which death and dying were simultaneously present and absent at the hospice. In the end of Part III, I use the concepts of smooth and striated to describe the contested practices within the hospice home, which on one hand create a permissive space for dying and on the other seek institutional striations to structure living and dying there.

7. MEDICAL PRACTICES AS RITUALS

7.1 Features of medical practices as rituals

Medicalizing and structuring effects

Living with advanced cancer is saturated with medicine, which affects not only the length and quality of life but also the everyday lived experiences of time, embodiment, and interrelationships. The medical regimen often comprises the frame for living, which then tends to define a big part of the experience of existence. This can be seen in the following case, when I was visiting Pekka at his home. We were sitting by the coffee table, having some sandwiches and coffee with his wife while chatting casually. Pekka started telling me:

> Pekka: I took a sleeping pill around midnight and then I woke up around ten o'clock and then I was groggy until four or five in the afternoon. You know, it was still affecting me, the medicine. I was walking around the house, bouncing off the walls (*menin pitkin seiniä*). Dang it, I was completely out of it!
>
> I: Do you take them regularly?
>
> Pekka: No, I take them only as I need them. Last night I did not take one, purposefully, since I wanted this day to go a little smoother. So, then I ended up tossing around in bed, half asleep, half in coma, for the whole night. I got up around five to read the newspapers…
>
> I: Is this kind of sleeplessness common?
>
> Pekka: It usually comes after the [chemo] drip, the worse one. So, they have ordered me cortisone. Yeah, cortisone. You know, it cheers you up, it gives you energy and drive! And when I quit that, then it goes like a rollercoaster down! So it goes back and forth.
>
> Wife: The spirits go down like the cow's tail! The first three days he is like a Duracell bunny, totally nervous and talking constantly, non-stop, and "should do this and should do that." But then after those three days, the spirits go totally down.
>
> Pekka: (grabbing his medical papers and looking at them) Here is something else they ordered me, too, the powder for the constipation. (Pekka/2)

Like for Pekka, drugs caused mixed feelings among the research patients. Yet, at the same time they were a major part of daily life and a constant topic of discussion—along with the various symptoms. Rauha, an elderly woman who was admitted to the hospice ward for a couple of weeks in order to "get her meds fixed," came to meet the day hospice group, telling, "Finally they managed to get the pain away. Oh, it was wonderful!" She continued, "It is amazing how much the human being can tolerate poison, if you just think how much I needed to take it before the pain was gone." The nurse playfully scolded her, "Rauha! It is not poison. It's *medicine*!" Everybody laughed. (D1: 15.)

The relationship my research patients had with their medicines was distinctive; it was close, even intimate. Vivian was very clear and explicit about her relationship with the medicine. On our last meeting, just two days before she died, she said to me that they should put a syringe

inside of her coffin.[144] "In honor of the medicine," she said, "since it was the medicine that gave me time and it was the life-sustaining element in my life" (D4: 29). Medicine was not "just medicine"; like Vivian said, it was "the life-sustaining substance" whose effects permeated all aspects of life.

Whether given palliatively or curatively, treatments and drugs easily become biomedical rituals (Brody 2010; Gordon 2015). Drugs are taken regularly, or when needed, according to prescriptions, while medical treatments such as chemotherapy or radiation are delivered in a ritualized manner in the ritual frame of a clinic (Elks 1996). One medical student commented on sessions of radiation, saying that going every morning to radiation therapy "does good for the patient," since it's *something to do* and keeps one busy. It's like going to work every morning, she said (D4: 12).[145] By implying that radiation therapy creates a meaningful program for the patient, the student accorded a medical ritual a specific *existential significance* or purpose, as if there was something to look forward to—in the form of the medicine.

This "looking forward to" aspect of the medical treatments was certainly true of my research participants. As long as there were treatments (and it did not seem to matter if the treatments were curative or non-curative), there was something to wait for. The feeling that "something was being done" meant that there was still hope. Inkeri described her disease trajectory (or medical path), which had lasted for about five years at the time of our meeting, by explaining how she had asserted her agency at various points by demanding more active treatments. After her cancer operation, she first received one kind of chemotherapy, and when that did not help her situation, she had another kind of chemo. Subsequently, she received three different types of chemotherapy, "one after the other on the list of the Current Care Guidelines," she described to me (Inkeri/1). The treatments worked for a while, until the tumor started growing again. Because the last round only gave Inkeri some unfortunate side effects without any medical benefit, the treatments were stopped. "After this," Inkeri told me, "I appealed to the doctors really hard, so that they would give me the kind of medicine that helps this illness for real" (Inkeri/1). She continued, "One winter evening they called me. I still remember where I was when they called. I was on a walk with a friend of mine. They called and told me that they had decided to give me one more trial of this chemotherapy, which I had hoped for" (Inkeri/1). The way Inkeri described the moment she received the phone call reveals how meaningful this trial was for her. The biomedical treatment had become a ritual of hope for Inkeri.

Since then, it happened a couple of times that a doctor cancelled or stopped her chemo sessions for "no obvious reasons," according to Inkeri; "although," she admitted, "of course there were all kinds of side effects, even some serious ones" (Inkeri/1). However, Inkeri was very persistent and believed still that the benefits outweighed the downsides. In that way, she

[144] In Finland, sometimes items of personal value (such as photos, letters, and material belongings) are put inside the coffin of the deceased before burial.
[145] Radiation therapy can be prescribed for different periods, from just a few times up to daily sessions for a month or so, depending on the nature of care as either palliative, disease-modifying, or curative.

continued to receive some more chemo and radiation therapy before arriving at hospice care. She told me that the medicine eased her difficult symptoms, but I thought that it certainly gave her also *hope* and *time*. Inkeri stated clearly to me that she wanted to keep living. "There was clearly a strong will to live," she explained when we talked about her past medical treatments; she continued that this will also prevented her from even thinking of death. (Inkeri/1.) In a way, it was impossible to commit oneself to both, to seek so hard to live and also to think of death. At least for Inkeri, she had to concentrate on one—and it seemed to me that it worked much like that for the other research participants as well.

By giving *rhythm* to the day, week, and month, medical treatment *structures* one's time and living—and hence, also, one's dying. Inkeri discussed this issue by reflecting on the structuring effect of her chemotherapy. For Inkeri, this not only concerned the actual chemo day and the following ones filled with fatigue and possible nausea, but, like Pekka explained, it was also about the cortisone days, when one was filled with energy. In reference to her last chemotherapy session, Inkeri said laughingly, "Thursdays are my cortisone days, and as I'm full of vim and vigor then, I do all my grocery shopping and fill my cupboards with food" (D2: 21). Cortisone affects mood strongly; many patients noted its positive effects, but a comedown was also experienced. Kimmo noted that every time his cortisone intake was reduced, he felt like he needed to start all over from the beginning (D1: 91).[146] Cortisone created cycles of being.

The downside of the strict scheduling in relation to medical treatments was that one was continuously tied to a certain time and place. Pekka commented that he would like to travel somewhere, or at least go to the summerhouse, if only there were no ongoing medical tests and treatments (Pekka/1). The way one chooses to orient oneself at the end of life defines, to a certain extent, what one will do—within the limits of one's abilities of course. That is to say, if one chooses the medically structured end of life, there may be less of an opportunity to engage with something or go somewhere else. Ritual striations can be made in many ways, but it is difficult to participate in more than one simultaneously. Furthermore, as Inkeri mentioned, it might be difficult even to think of death if one is still strongly oriented toward future life.

The biomedical orientation also leaked into daily *language*. One day I was talking with Aili on the phone, and she was telling me about some new pains she had recently had. Attentively, I asked her if she was sure she had all the medicines she needed. As soon as I said that, I realized that while I was trying to be compassionate to her, I actually started "talking medicine," expressing empathy via medical discourse. I recognized that I had learned this from the day hospice, where news tended to be exchanged through medical talk (about exams, medications, blood tests, and so forth), and reactions and emotions were also expressed in these terms. It was common for patients, volunteers, and staff alike to start the conversation with a question relating to a medical ritual, such as "Did you get your tests results already?" or "How is the new

[146] Widely used in the treatment of advanced cancer, cortisone has been proven to reduce fatigue and help with appetite loss (Paulsen et al. 2014).

medicine for you?" After a while in the field, I had to learn *not* to reproduce this sort of discourse, in order to give patients the chance to begin speaking about anything they wanted (not only a medical issue).[147] In practice, however, the conversations often did revolve around the medical details of being. My research participants were socialized in relation to medicine and, like me, they had internalized the medical way of talking and medical way of assessing their reality (Hofmann & Svenaeus 2018).

One significant aspect of medicalization in regard to actual dying was the way in which many of my research patients at the hospice home talked about palliative sedation, which refers to "the use of medications to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life" (Olsen et al. 2010: 949). Especially patients who feared suffocation (often due to the location of the tumor) told me that when they had voiced their fears at the hospice home, they were promised that in an extreme case they would be sedated. At least Aili (D4: 17–18), Taina (D1: 134), and Vivian (D4: 27) talked about this, but it was also something that was mentioned in the common conversations in the day hospice (D4: 17–18). One time in the day hospice, Taina declared in passing but with determination that when it was her time, "I will be put to sleep." The nurse was quick to correct her expression, "you mean *sedated*" (D1: 134). I had an impression that already the promise about palliative sedation calmed fearful patients, yet actual sedation did not necessarily happen very often (D1: 37).[148] This was the case with Vivian, for instance; she relied on the knowledge that she could get sedation, if necessary, but it turned out that in the end she died peacefully without any need for that.

To summarize, all these various biomedical practices—including the medical discourse, the actual treatments, and the drugs, but importantly also the care plans—formed a sort of manual for "how-to-live-with-incurable-cancer."[149] As such, biomedicine affected the participant's physical comportment, virtues, skills, disposition, specific emotions, attitudes, and so on. This mirrors anthropologist Talal Asad's (1993) definition of ritual. Similar to Bell's practice-oriented view on ritual and Foucault's idea of technologies of the self on one hand and docile bodies on the other, Asad sees ritual as a *learning process* imbued with complexities of power resulting in both potentialities (*potentia*) and force (*potestas*). Via such negotiations as

[147] I had to teach myself to open a conversation in a purposefully open-ended manner, such as "How is everything?" (*Mitä sulle kuuluu?*) instead of talking directly about the patient's medical condition. Sometimes I asked patients "How are you feeling today" (*Miten sä voit tänään?*), so that they could tell about their situation from whatever perspective and level of intimacy they chose.

[148] A recent study among Finnish nurses shows that palliative sedation is thought to be a very useful tool (although it is not practiced very often); however, according to the study, it caused moral distress among nurses who were in need of additional education about the method (Nissinen et al. 2019).

[149] In his postcolonial perspective on ritual theory, Asad reminds that the present understanding of ritual as a type of behavior or activity was formed only around the turn of the 20th century (around the same time as the modern "self" came to be interiorized as an internal consciousness rather than an external display of actions; see Asad 1993: 26; Mahmood 2001, 2005; Keller 2002: 64–65). Prior to that, ritual was seen as "a script for regulating practice," a manual "including texts to be uttered and instructions on how and by whom, as well as on the accompanying actions" (Asad 1993: 26).

demanding, consenting to, and resisting treatments or whole care plans, the research participants practiced their agency and learned (or perhaps rejected) the inscriptions of the ritual. Consequently, they learned to live and to interpret reality accordingly, to speak and to act in accordance with the biomedical worldview presented by these rituals. In this way, biomedicine became a cultural belief system to some (van der Geest 2005).[150]

This is exactly what Schilbrack regards as "metaphysical learning" in the ritual (Schilbrack 2004). When patients consented to biomedical rituals, they learned to be in alignment with the medical reality, and they learned to perform correctly in various ritualized situations (such as diagnostic examinations, radiation therapy, and so forth). Learning was not limited to the realm of medicine but transferred to other aspects of life as well. As we have seen, patients tended to think of themselves, their bodies and minds, their time and their doings, in terms of medicine. Medicine colored language and became the topic of conversations; care and feelings of empathy could be expressed via actual medicine or by references to it. In this way, the research patients participated also in the metaphysical world-ordering of the medical ritual. Furthermore, ritual not only conveys certain definitions of reality (as ideologies), but through embodiment it quite literally materializes, mediates, and thus also constructs those ideologies "into the flesh" (Bell [1992] 2009: 191–193).[151] Attending to these kinds of rituals, however, first requires trust.

The element of trust

Trust was a regular theme in the conversations I had with the patients, especially on the oncology ward. Many patients there, such as Martti, emphasized what great care they had received on the oncology ward, and how they trusted Finnish cancer care (Martti/1). Inkeri and Helena also talked about the importance of being able to trust their medical caregivers. Helena pointed out to me that trusting her doctor freed energy for her, as she did not feel like she needed to bear the responsibility for her medical decisions (Helena/1). The trust was not self-evident among everyone, though. As mentioned already earlier, Inkeri told me about a patient support group that she had attended earlier in her illness trajectory, where there had been a lot of rather negative speculation about doctors and different treatment plans (Inkeri/1). Inkeri had stopped attending the support group for this reason; she wanted to protect herself from that sort of negativity: "I constantly wanted to emphasize the issue of trust, that there needs to be trust, that otherwise one cannot make it through this" (Inkeri/1).

Anthropologist Maurice Bloch (2005) claims that rituals are ultimately about *deference*, which he defines as "acting or speaking in certain ways for reasons which one does not explain in terms of personal volition, intention or understanding but in terms of implicit or explicit *trust in others* who one 'follows'" (Bloch & Kallinen 2017, italics mine). Approached in this way,

[150] On the relation and similarities between religion and medicine, see, for instance, Vellenga 2008 and Goldberg 2007.

[151] Bell (2009: 108) writes that "the purpose of ritualization is to ritualize persons, who deploy schemes of ritualization in order to dominate (shift or nuance) other, nonritualized situations to render them more coherent with the values of ritualizing schemes and capable of molding perceptions."

rituals can point to sources and objects of faith, trust, and hope, thereby illuminating the kinds of connections one seeks to cultivate, especially in times of crisis. Studying rituals may, of course, also reveal conflicted and contested ideas about trust in a given situation. One way or another, however, some sort of authority is practiced, and trust is cultivated in ritual activities.

Most of my research participants had strong trust in the medical system at large, but specifically also in the power of medicine. Pekka, for instance, explicated his trust in Finnish medicine when we were talking about his illness trajectory at the ward. Pekka told that soon after a scan had revealed a large mass in his torso, he was scheduled for a cancer operation. The surgeon had made an insertion—only to close it again. The cancer had spread everywhere. After the operation, when Pekka asked the surgeon how much time he had left, he was told that he probably had less than six months to live. During his last months, Pekka underwent a number of medical treatments and interventions. He received radiation therapy and three different kinds of chemotherapy, and during another operation a biliary drain was inserted in his gallbladder. He was taking a number of different drugs, some of which were prescribed to counteract the side effects of others. He had blood tests and medical procedures almost weekly, and occasionally he had to rush to the emergency room because of a fever or other complications. (Pekka/1, Pekka/2.) When I spoke with Pekka about his situation, he confessed that he was not overly interested in the medical details of his care planning: "Usually the doctor says his own opinion and I say 'Whatever, it's all the same for me. Let's do that.' I trust that they know better than this kind of layman" (Pekka/1). Pekka also referred to the superb level of cancer care and cancer research in Finland.

Pekka fully embodied the given world-ordering of the medicine. However, while believing in and living the medical reality, at the same time Pekka also lived in another metaphysical frame. As a born-again Christian, Pekka was confident that however his future would unfold, ultimately it was all going to be okay, "I have made peace with the upstairs," he confided (Pekka/2). Maybe this played a part in his seemingly relaxed attitude: there was a divine source for his ultimate trust. Pekka was able to immerse himself simultaneously in the causal world-ordering of medicine and the participatory world-ordering of Christian faith.

Pekka's trust toward the medical system lasted until the end. When Pekka eventually lost his appetite and stopped eating and his state of consciousness became fuzzy, Pekka's wife requested home care. As mentioned earlier, Pekka wished to die at home since he detested hospitals and believed it would be easier for his beloved dog. Two days later, Pekka's wife told me, she had to leave the house for something, and her teenager stayed at home (D4: 32–33). At first Pekka was reading the newspaper, but then his eyes glazed over and he became unresponsive. The son called the home care. When they arrived, they administered some pain medicine and started planning for his transfer to the hospital (despite his wishes to die at home). The home care called an ambulance, whose emergency medical technicians gave Pekka oxygen to ease his breathing. Pekka's wife was called home. Pekka was very anxious, but as soon as

his wife arrived he calmed down. Due to his rapidly deteriorating condition, the medical staff decided to keep Pekka at home. He was given some slightly sedative medicine and his wife had time to call their closest friends and some nearby relatives to come over to say final farewells. At the moment of death, his wife held him and hummed calmingly. "As soon as he was gone, the dog started crying and whining. She knew," Pekka's wife told me. After Pekka's death, the dog adopted Pekka's special pillow, which his wife had made him and which he had carried with him everywhere during his whole illness trajectory (I had seen it at the hospital). From then on, the dog slept always on it, the wife told me. (D4: 32–33.)

Pekka was able to die at home in complete accord with his wishes. His actual moment of death was affected by medicine—as was his whole process of dying. Since he was at home, however, his wife was able to provide the ideal context for Pekka's death. Their closest friends and relatives were able to say goodbye to him, much like in the pre-industrial time in Finland, when ritual farewells were a general custom (see Pentikäinen 1990: 65–66). Pekka's dog was there with him, just like he had hoped, and his wife attended his death.

In regard to the cancer care, Pekka gave authority to his doctors by resigning from the decision-making. When it came to his death, however, he did not ask the doctor's opinion but was determined. Here he used his agency and he died at home, as he wished, away from the hospital.

From the perspective of a dying person, the challenge of a biomedical ritual frame is that in biomedicine, death represents a defeat. Intuitively, medicine's goal is to sustain life, just like Vivian noted when commenting on the importance of medicine to her. Now that palliative medicine has become more developed and common, it can be difficult for a patient to reconcile the seeming ambiguity and tension between medicine and death. From this subjective perspective, many personal rituals can help the patient's endeavors to understand their situation. Personal rituals vis-à-vis dying often attempt to seek control in a chaotic and often frightening situation, such as when one receives a terminal diagnosis and encounters the fragility of existence (Giddens [1991] 2006: 35–40). These rituals also tend to revolve around the question of trust. This is not surprising, since, in addition to Bloch's references to trust, the connection of ritual with belief systems and ideologies is established in many ritual studies (Bell [1992] 2009: 182–196).

Contested ritualizations

From the objectifying perspective, ritual can be seen as a way to impose (elements of) a worldview upon its participants (Bell [1992] 2009: 171–191). According to Bell, this process of internalization is often interpreted as rather mechanical by nature, with ritual being "a single central mechanism for the communication of culture, the internalization of values and the individuals' cognitive perception of a universe that generally fits with these values" (Bell [1992] 2009: 176). By contrast, Bell ([1992] 2009: 189–191, 214) stresses that any ideological learning that may happen via ritual is always negotiated, and hence consented to or resisted by

its participants. While this is true, I would not underestimate the effect of embodied—sometimes even rather mechanical—practices; learning often happens by becoming accustomed to things and doing things in a certain manner. The reflective, critical mind does not always play such a great role in the process.

The process of consenting or resisting can be seen, for instance, in the way that patients related to their hospital clothing (Lämsä 2013: 51).[152] Some, like Martti, quite happily embraced it; he told me outright that he thought of the hospital clothing as "a ritual" (D3: 35). While getting undressed from his normal clothing, he explained, he sort of undressed from his normal identity, assuming the identity of a patient in the form of the hospital clothing (D3: 35). Martti said that the hospital clothing was a good thing; for him it seemed a relief to give up some of his personal identity, responsibility, and authority, in order to be a part of the medical ordering of reality—and in order to be cared for. Others (like Peter, for instance) resisted the practice, perceiving it as degrading and patronizing. There is always some degree of negotiation involved in ritual. Instead of seeing ritual as symbolically or concretely modeling the (social) reality for participants to internalize, Bell ([1992] 2009: 195) suggests that essentially ritual neither refers to nor symbolizes anything outside of itself; rather, *reality gets to be constructed and defined within the ritual activity itself.*

Sometimes a patient, as a ritual participant, challenged the medical institutional practices and claimed agency for themselves in order to define their own reality by creating an alternative frame of action that was more suitable for their own designations. This happened, for instance, when Peter refused to be a "hospice patient" and "denied" the *role of dying* suggested by the hospice (Noyes & Clancy 1977; Parker-Oliver 2000), and instead created his alternative interpretation and frame of action. Peter felt himself as a visitor in the hospice home where "the others" were frail and dying, whereas his aim was to "rehabilitate" himself, "get over this," and "go home and back to business" (D1: 58–59, 70–71). To support this aim (as described already above), he furnished his personal space with various items from his work and previous lifestyle. Piles of work papers and his computer monitor competed for table space with a hospital sippy cup, food trays, and a bedpan (D4: 11). He would engage with his personal items by either concretely fingering them or referring to them in his speech. In this manner, Peter sought to claim agency over his reality, while via his language he created his own version of the metaphysics of life and death. In the permissive atmosphere of the hospice home, Peter sought to mediate his being in the way he wanted, which was via his personal apparel rather than via hospice-style "soft medicalizations."[153]

[152] The issue of patient clothing is naturally manifold, and besides the perspective of good hygiene it includes matters of equality, anonymity, depersonalization, and control, as discussed in a recent article "Patient Clothing – Practical Solution or Means of Imposing Anonymity" written by experts in the field of medicine (Bergbom et al. 2017; in reference to Finland, see also Topo & Iltanen-Tähkävuori 2010).

[153] Many of the medical facets of care in hospice have been "softened" in comparison to their original medical versions. For example, in the hospice home the volunteers may make nice-looking little sachets for their urine

Of course, as in Peter's case, some patients never conform to the role of a dying person or that of a *sick person* (Parsons 1991; Schipke 2019) with the (pictured) external signs of weakness, frailty, and a loss of vitality.[154] One example of resistance toward the common (or commonly imagined) aesthetics of a "sick person" is found in a text by the Finnish musician and author Astrid Swan, who writes about her body before a cancer surgery:

> The day before my surgery I painted my nails orange for courage and had my hair cut and dyed into a beautiful blond bob. It was me not wanting to give in to ugly sterile hospital freak-out. It was me both trying to lie to myself about how scared I was and to maintain control by not losing beauty. Because sometimes beautiful things bring peace where chaos resides. I made a friend at the hair salon. (Swan 2017)

Before her mastectomy, the artist sought to practice agency and empower herself with rituals of beauty. Although she seems to doubt a bit her ability to do this, since she notes that she is "trying to lie" to herself about her situation, I would still say that the actual doing of the ritual of beautification (or writing about it, as a virtual reality) was already making a difference. As Bell claims, reality is constructed and defined within the ritual activity itself. Ritual practices power rather than disguises it: "Ritual is the thing itself. It is power; it acts and it actuates" (Bell ([1992] 2009: 195).

7.2 Power, agency, and the body

Ritual, power, and distributed agency

Instead of seeing power as something that one can possess, nowadays it is common in the social sciences to comprehend power as something that prevails and happens in social customs where institutional practices and private bodies come together (James & Hockey 2007: 35).[155] Much of our present understanding on the ways in which societal power operates owes to Foucault, whose broad studies on the histories of mental illness, sexuality, medical perceptions, and penal systems have changed the way in which modern people see themselves and the world around them. As Bell ([1992] 2009: 202) emphasizes, for Foucault "the body is the 'microphysics' of

bags—for the enhancement of dignity. In hospice, patients do not need to wear any institutional clothing, unlike on a hospital ward. These are representations of Deleuzoguattarian smoothings, which the patients themselves can also promote, contest, or alter through their own actions.

[154] The concept of the *sick role* was introduced by sociologist Talcott Parsons already in 1951. According to Parsons (1991: 294–295), like any social role, the sick role also creates rights and duties. The first right is that one has the right to be freed from social obligations, such as work, without any retribution; the second one is the right to be cared for. The duties of a sick person are also twofold. Because society regards illness as an undesirable state, the patient must wish to get well; secondly, one is expected to seek help from competent professionals and to engage in treatment (Noyes & Clancy 1977). Later, Russell Noyes and John Clancy wrote about the importance of separating the *dying role* from the *sick role* (Noyes & Clancy 1977). Since then, it has been suggested that hospices are in a crucial role in socially transforming the sick into the role of dying (Parker-Oliver 2000). The understanding of patient roles nowadays accentuates their contextual and fluid nature (Schipke 2019). The most recent addition in the conversation proposes a new intermediate role, namely, the *chronic sick role* constructed by the medical system (Schipke 2019).

[155] As Foucault states in the *History of Sexuality* (1978: 93), "Power is everywhere: not because it embraces everything, but because it comes from everywhere. […] Power is not an institution, nor a structure, nor a possession. It is the name we give to a complex strategic situation in a particular society."

the micropolitics of power." Methods and techniques used for "the meticulous power of the operations of the body" (Foucault [1977] 1995: 137) include organizations of space (such as locating individuals in their own places and creating functional spaces like hospitals and hospices) and imposing bodily acts and gestures (Foucault [1977] 1995: 141–156). These methods and techniques become visible and are recognizable in various institutional and medical practices. According to my research participants, at times these became objectifying.

The following conversation discloses a medical situation in which the ritualized encounter between the physician and the patient failed from the patient's point of view, causing her distress. In fact, it was perhaps exactly the *deviation* from the ritualized form of a communication that engendered this misunderstanding. This is possible since the ritualization of a doctor's consultation can effectively protect both of the participants in the situation, the doctor and the patient, since both have their given roles to take refuge in during what can be a very challenging encounter. This experience seemed to have been very significant for Vivian, since she referred to this event several times during our meetings. It is good to bear in mind that this consultation was traumatic to her in every possible way, since it was the moment when she learned that her curative treatments would be stopped.

> Vivian: It was a terrible shock that they were going to stop the treatments… (becoming emotional)
>
> I: So you heard it at the clinic?
>
> Vivian: Yeah…
>
> I: And then they sent you here, to the hospice?
>
> Vivian: I was in the doctor's consultation room. And the doctor told me that the treatment will be stopped. I returned to the hospital room. I was going to go to radiation but they cancelled it. [The doctor said] it was better to insert a drain and remove the fluids so that I could breathe easier. And then the doctor came back to the room where I was, and said to me: "Oh, I forgot to mention to you that you won't be resuscitated. So, that if the heart stops, they won't… like, you will not be… That it is the condition for that… something." (trying to remember what the doctor's words were exactly) And I imagined there that since I was going to the drain insertion, it was likely that my heart will stop.
>
> I: This was how you heard it?
>
> Vivian: Of course! That's how I interpreted it. "Yeah, I forgot to say…" That it was important to say that, before I go to the drain insertion, that if the heart stops then I will not be resuscitated. And then I will be moved to the hospice home…

The decision not to resuscitate Vivian, which she refers to, relates to the "do-not-resuscitate" (DNR) order that is included in the end-of-life decision (*saattohoitopäätös*). It had nothing to do with the drain insertion, but since Vivian was in shock after hearing the news about her situation, she misunderstood the doctor's words completely. Had the doctor explained this in the usual manner in the ritualized frame of the consultation room, this kind of misunderstanding would perhaps not have taken place. This is a good example of how rituals in medical

surroundings can protect not only the medical staff (e.g., by constructing some professional distancing) but also the patient. In the spatially ritualized and organized consultation room in the presence of the familiar—and, as we have seen, usually trusted ritual symbols (such as the doctor's white coat)—it *might* have been easier to receive and process the difficult news. Indeed, according to the previous research, the single concrete element that was found to have great importance in the way how patients received bad news was for the delivery of the news to happen "in a quiet, private room with sufficient time so that the HCP [healthcare professional] did not appear rushed" (Matthews et al. 2019: 2292). For Vivian, however, this encounter was not only about a misunderstanding in communication, but also about an experience of objectification.

Based on the conversations with my research patients, objectifying attitudes and practices—including gaps in communication—were generally tolerated to some extent, especially when the care was still curative. At that time, the medical task of curing was regarded as so valuable that communications skills were not always thought of as a priority.[156] This is not to say that patients did not encounter excellent care with a course in specialized medicine; on the contrary, the quality of cancer care, for instance, was greatly praised by my research participants (such as Martti, Helena, and Inkeri). But neither does it mean that patients did not suffer from possible objectifying encounters either. Along their illness trajectory, patients longed for supportive and caring encounters with medical staff, as the case of the trusted doctors demonstrated. However, especially at the moment of a terminal prognosis, the encounter with medical staff becomes significant in an entirely different manner. While the (unrealistic) hope for a cure sometimes continued to exist for my research participants, the hope to be heard and seen, to be cared for and respected, now became even more important.

Rituals abound with questions related to trust, power, and agency. Simply put, agency can be defined as "the ability to transform the world" (Sax 2006: 474). Following the logic of a relational subject, rather than seeing agency as strictly subjective it should be understood as something distributed among various human and non-human actors alike (Gell 1998; Latour 2005: Enfield 2017). In regard to ritual agency, anthropologist William Sax points out that agency is distributed in networks among persons, institutions, and practices—including rituals (Sax 2006: 477–476). Subsequently, various aspects of medicine—its practices, discourse, human and non-human actors, and spaces—can be seen as empowered with distributed agency.

From the angle of critical theory, Asad argues that subject and agent should not be coupled in an unproblematized manner (Asad 1993: 11). Asad does not claim that a person can lack agency; instead, he questions the traditional understanding of subjectivity in general. Humans are not self-constitutive. As Asad puts it, social relations, language, and the body's materiality shape the person in such a way that "few would claim that the human agent is sovereign,

[156] Helena, for instance, mentioned that she did not have huge expectations for the doctor to be so empathetic regarding her psychological wellbeing; instead, she described the meetings as "very efficient," and for her it was fine like that. She had other avenues of emotional support.

although post-Enlightenment moral theory insists that she ought to be autonomous" (Asad 1993: 10). In this way, Asad promotes a notion of agency in which, as anthropologist Mary Keller puts it, "power is not located in the individual consciousness of an 'agent' but rather *in systems that authorize discourses and in disciplinary practices* such as are found in religious traditions" (Keller 2002: 64, italics mine). It could be—and has been—argued that in today's world, medicine practices a somewhat similar authority as religion in this regard (Turner 1995: 35–36). Medical science tells us what the healthy—and good—lifestyle is, not only by defining praxis but also by creating discourse and attitudes around it, at times taking a moral tone (for instance, in relation to smoking).

In sum, there was a certain amount of agency in the ritualized practices themselves, which at times ended up affecting the patient's experience in a remarkable manner. However, even more tangible was the relation between the patient's body and the medical rituals, which will be looked at next.

Body, illness, and techno-medical agency

For Bell, Asad, and Foucault alike, the key notion in rituals and power is the body. Subsequent to the work of these authors, our bodies have become increasingly *posthuman*. By differentiating between a postmodern and a posthuman body, it is possible to explore how biotechnology has affected people's actual physical reality and the embodied being-in-the-world, not only in how things are perceived but also in the actual way people exist. In the realm of medicine, medical technologies both shape the lived experience of illness and affect the way people understand themselves and their bodies (Hofmann & Svenaeus 2018).[157] The intertwined connection of self-image, illness, and the aspects of medicine becomes evident in Helena's narrative. She told me about the moment when she learned that the tumor in her chest—now removed by the surgery—had been over ten centimeters in diameter:

> How was it even true? I somehow felt *shame*. Learning about it caused different kinds of emotions in me, but mostly shame. Like, how is it possible that one has a ten-centimeter tumor in them and one doesn't even notice it!?! (Helena/1)

The surgery had revealed something about Helena which she had not been aware of before. The details about the tumor changed the way in which she thought of herself. Upon hearing the news, Helena felt estranged from her own body and even ashamed of the things it was doing without her awareness.

[157] In their insightful article, philosophers of medicine Bjørn Hofmann and Fredrik Svenaeus (2018) analyze the shaping effects of technologies on the experience of illness in an interesting manner. They show how technology and its applications can easily become part of—or even replace—the experience of illness. They also note how technology changes bodily self-conceptions in illness. Hofmann and Svenaeus (2018) also point out that people are more inclined to assess their life situation on the basis of medical criteria. This is not surprising when one is sick with cancer, but as I noted above, the pervasiveness of medical language in communication in general is nevertheless remarkable.

As we have already seen earlier, shame can make up part of the illness experience in various ways. The feelings of shame can be understood in terms of Giddens' concepts of bodily self-management and self-identity. As Giddens writes, "The regularised control of the body is a fundamental means whereby a biography of self-identity is maintained," while shame is "essentially anxiety about the adequacy of the narrative by means of which the individual sustains a coherent biology" (Giddens [1991] 2006: 56–57, 65). In other words, when one's bodily self-management becomes fractured or is revealed to be a mere illusion, it threatens one's self-identity and ontological security, and it may result in feelings of shame. One's physical reality is not what one believed it to be. Here medical technologies (for instance in the form of diagnostics) can have significant agency.

In Helena's case, both the illness itself and the medical technologies involved in her care affected her whole existence and the lived experience of it. Over the course of time, during her illness trajectory, Helena started to feel that she had "lost" her own body. When I asked her what she meant by that, she explained:

> The most concrete thing at first was, of course, the loss of the breast [in surgery], but that wasn't so big of a deal for me. […] But then… First it was the chemotherapy and the cortisones which cause many to gain weight. I was one of those. And then, when one is very sick, one moves quite little… There are many factors. One does less sports, the drugs lead to weight gain, and there is the comfort-eating. […]
>
> All of this was going on and when the adjuvant hormonal drug therapy started, I was getting fatter before one's eyes… The body felt alien since the weight gain… and then there were those pains… Those pains… Everything changed. I could not fit into my old clothes anymore, but I did not feel like buying any clothes either; I did not want to go to the store, to those fittings rooms…
>
> It was like my body became this strange *blob*; from the neck down it was like some blub, something completely alien, which I did not even want to get to know. The connection [between mind and body] was broken. But since a human being is a whole and one cannot separate body and mind… This was a terribly big thing. (Helena/1)

After this description, Helena proceeded to tell me about the unpleasant sensations of hot waves she had, related to the early menopause caused by her medical treatments.

The posthuman perspective questions the autonomy of the subject more than earlier postmodern theories, which have remained human-centered (Sharon 2014). In posthuman thought, the intentionality of various technologies is understood to be as significant as human intentionality—they guide our understanding of the world in a remarkable way. Accordingly, medical biotechnology, including diagnostics and actual therapeutics such as various kinds of drugs or radiation therapy, constitute medicine but also our medical selves. As we have seen, medicine and medical devices became physically and intimately fused with the bodies of the research participants. When Eeva finally received a drug infusion pump (or "pain pump") about four weeks before she died, she felt as if her whole existence changed for the better. Since her pains were now lessened, it was easier to eat and swallow—and just simply be. Her embodied

reality changed drastically. She told me that it was not just about her body, as her whole state of mind became different; according to her, this was thanks to the pain pump. (D1: 139.)

What is important to note here is that with their "artifactual intentionalities" (Sharon 2014: 146), various types of medical technology, such as imaging technologies, not only *reveal* things about the body but also *construct* it, bringing information that was otherwise unknown. For example, computer imaging or other forms of diagnostics produced representations of reality that sometimes contrasted with the lived, embodied reality of the patients themselves. Vivian considered herself rather knowledgeable and conscious of her body and whatever was going on with it, but with cancer her trust in her embodied sense of reality collapsed totally:

> It has been quite weird… I have always thought that I could trust my own sensations. Especially since I have been such a sportive person who knows her own body. That one is able… When the first round of chemotherapy was over, I felt myself completely healthy. And I believed I was going back to work. I felt myself so alive, something I had not felt for a long time. But the disease was there in the background, even though I did not know about it. It was so contradictory then, that the whole sensation was so completely erroneous. The cancer had advanced, even though I felt myself healthy. (Vivian/2)

Vivian learned about her real situation only after the CT scan revealed that the chemotherapy had not worked and her cancer had spread.

Different aspects of medication together comprise the agential force of medicine, which constituted the patients' everyday being. For example, some of my research participants suffered from the kinds of side effects of the drugs and treatments, which considerably affected their everyday life (D1: 68, 74; D2: 19, 21). Vivian, on the other hand, told that she had felt great during her chemotherapy (Vivian/2). At times, it was difficult—if not impossible—to discern which physical effects were caused by the illness itself and what was a side effect from the medicine; however, these effects together could become so heavy that the patient momentarily thought of death as an easier option than life.

At one point in his illness trajectory, Martti was in very rough shape; he could not even eat by himself but was fed with a tube in the hospital. Later, he described, "At that moment the world became a very thin place" (D2: 79, 100). This was the moment when he thought of giving up. Martti overcame this worst moment, however, and recovered. My mother also started to talk about death as a relief during the most difficult moments of her illness. In the end, of course, it is difficult to estimate whether it was the illness or the medical treatments that fatigued the patient the most; it could have possibly been a combination of both (Lawrence et al. 2004).[158] However, the fatigue that is associated with cancer and its treatments tended to be a common topic of conversation among the hospice nurses and also among the patients, for instance, in the day hospice group (D2: 78).[159] For example, Taina talked about depression, apathy, and her

[158] On the multifactorial causes of fatigue, see Bower 2014.

[159] While I cannot make estimations from a clinical point of view about the possible psychological states which my participants had, they did talk about fatigue (*väsymys*) a lot, and they tended to lump various kinds of emotions

inability to get anything done mostly as a physical reality, while Aili proclaimed that it is not just physical but also psychological: "When the dark moment comes at some point, then it becomes difficult. There comes the feeling 'what for?'" At one point in her illness trajectory, Aili was clearly distressed and even hoped for death, so she could "just sleep away one night" (D1: 107–108).[160]

One obvious facet of the human body, which was not commented on very much in the field, is that of sexuality. Perhaps because I did not actively pursuit this theme, it rarely surfaced in the discussions with my research participants—Helena and Heikki were exceptions in this regard. With Heikki, the topic came up in reference to the issue of an orchiectomy (see Chapter 9), whereas Helena openly mourned for her previous embodied reality: the loss of her sexuality and her well-functioning, fit body. The "lost body" was something that others also commented on by expressing sadness over their diminished physical capacities. This came up especially with men, such as Oiva and Kimmo, who had led physically and sportively active lives (D1: 8, 74; D4: 5), but on multiple occasions women such as Aili commented as well on their lost physical abilities (D1: 108).

In regard to her grief about her "lost body," Helena felt that since she had cancer, there was no room for any other complaints, such as menopause: "One was supposed to be ever grateful for simply being alive" (Helena/1). In Helena's experience, the materiality of cancer and the physical changes and losses it wrought were not among the topics of conversation that her peer patients engaged in. Furthermore, Helena thought that the frail and changing body of an aging woman was taboo in the society which valued youthful health so highly (Helena/1). Indeed, the aging female body can be seen as the archetypal vulnerable body (Oksala 2013).

The disciplined, dependent, and vulnerable body

When my mother received her diagnosis of advanced lung cancer, she was referred to various medical treatments. First, she underwent one round of chemotherapy, and when that proved to not have the desired treatment response, she started an intense period of daily radiotherapy. One day she commented on her therapy, where she had been that morning, by complaining that her body "was not able to obey" the nurses. By this, she referred to her body not staying in the necessary position on the table, in alignment with the radiation beams. She sounded almost guilty that she had not been able to perform correctly for the ritual of radiation therapy.

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under that term. It is acknowledged that "cancer-related fatigue might have physical, mental, and emotional manifestations, including generalized weakness, diminished concentration or attention, decreased motivation or interest to engage in usual activities, and emotional liability"; furthermore, "although cancer-related fatigue shares some characteristics with depression […], patients experience fatigue as a distinct and central symptom that impairs mood and functional abilities" (Bower 2014). I do not suggest any diagnosis here, but I simply reiterate what was told to me in the field.

[160] "To sleep away" (*nukkua pois*), comparable to the English expression "to pass away," is probably the most used euphemism in Finnish for dying.

One's exact body position is regarded as extremely important in radiation therapy for the sake of the actual efficiency of the treatment, but also for protecting the patient from any possible adverse side effects.[161] To ameliorate the precise positioning of the patient's body, various kinds of immobilization devices are used, such as masks and body molds, depending on the location of the tumor to be irradiated. A common procedure is to make tattoo marks on the skin to outline the treatment field, although some of the newer technologies no longer require this (Moser et al. 2020). From the patient's subjective perspective, it is understandable that a highly technological radiation therapy associated with cancer can be a frightening and anxiety-causing experience. This is well recognized in the field of oncology. Certain elements, such as the use of immobilization devices, have been found to be a possible cause of severe anxiety for patients (Clover et al. 2011; Mullaney et al. 2012). Furthermore, worry about the treatment equipment, the general difficulty to tolerate the overall treatment experience, or feelings of isolation or claustrophobia within the treatment room have all been shown to be significant factors to increase patient-reported situational anxiety levels (Mullaney et al. 2016).

Without overlooking the medical significance of radiation therapy or underestimating the importance of the exact placement of the radiation beams, and thus the precise position of the patient, I wish to draw attention to some of the underlying relational dynamics in the treatment situation. This is important since (as discussed in Chapter 2) once the patient has entered a medical relationship—with staff members, the place, the treatment plan, etc.—these various affective relationalities commence to affect the patient's everyday life in a remarkable manner.

As we have seen, during their illness trajectories, the patients learned to talk and "do medicine" by becoming socialized into the medical world-ordering. One aspect of the socialization has to do with the appropriate medical language; another aspect involves the learned correct physical comportment. My mother's comment about her "disobedient body" echoes Foucault's description of power that displays itself in small, everyday practices, operating via ritualization.[162] When learning to behave according to medical expectations, the patient's body tends to become a docile body; Foucault (1995: 136) describes "the body as an object and target of power […] that is manipulated, shaped, trained, which obeys, responds, becomes skillful and increases its forces."[163] This kind of training can happen in the embodied disciplinary practice of a ritual (Asad 1993: 33).

Now, from the medical and clinical point of view, it is of course crucial that a patient learns to perform in the required manner, depending on the situation and the medical task. To be successful, the medical examination and procedure simply *need* the patient's body to behave in

[161] See OncoLink Team. (2020).

[162] Power itself is not "good" or "bad." From a Spinozian point of view, it always has both qualities, that of force (*potestas*) and of potentiality (*pontentia*). As discussed in Chapter 2, per Foucault, power is more of a strategy than something possessed; furthermore, power is everywhere in the discourses and practices of the society (Foucault [1977] 1995: 26–27).

[163] In particular, Foucault analyzes the formation of the disciplined docile body in the army and elementary schools, but the same comprehension of the body is also developed in relation to therapeutic environments (such as a hospital) and the economic system of capitalism (Foucault 1995: 138–139; Schwan & Shapiro 2011: 100).

a particular way. At times, this comportment can be difficult for the patient to achieve, due to such reasons as physical incapacity, pain, or fear. The emotional situation may become further complicated when the patient, like my mother, clearly understands the importance of the correct behavior yet is unable to perform in the prescribed way. With time and practice, however, patients adapt to the new ways of doing things (within their personal limits, of course) and start gradually embodying new skills. Medical encounters are always constructed from various perspectives coming together; there are as many perspectives as there are actors. The perspectives are not reducible to each other but bring forth their own embodied information about the situation.

From the point of view of ritual theory, medical encounters can be approached as a ritualized process with various actors. Bell's conception of *ritualization* clarifies how in these processes, small gestures and ways of doing things unobtrusively transform and solidify behavior and responses into correct and appropriate ways of doing things (Bell [1992] 2009: 109). A medically disciplined body thus learns via ritualizations to respond correctly to various inputs—such as radiation therapy. At this point, the patient's body is becoming not only Foucault's docile, disciplined body but also the dependent body, per Feenberg (2006).

As explained in Chapter 2, Feenberg's analytical model of the dependent body describes embodied being, which invites actions on the body by others. Patients are by definition in a dependent position; according to Merriam-Webster, 'patient' is defined not only as "an individual awaiting or under medical care and treatment" but also as "one that is acted upon."[164] Feenberg depicts this act of inviting as voluntary and something that can be switched on or off. To a certain extent that applies here, but I would suggest that the situation may be much more nuanced and complicated. The moment a person surrenders their body to be in a dependent position, the issues of power and agency become significant elements in the relationship. Once the relationship is charged with an issue of power, the nature of the relationship inevitably changes. A dependent body is essentially vulnerable; in addition, relations with a vulnerable body are always a matter of ethics. Furthermore, because of the power practiced in the relationship, a dependent body may not necessarily be able to exit the situation that easily. To assume otherwise would be to argue for the idea of an autonomous independent self (capable of complete sovereignty), which is an abstraction that fails to realize itself—especially in the context of (terminal) illness. To expect the patient to act as an independent subject in their relationship with medical authorities contradicts the whole concept of *patienthood*, which is based on the very relationality between the two (the sick person and the caring agent).

Vulnerability can be seen as a universal element of a human body. Philosopher Judith Butler (2004: 31) writes that we all share "common human vulnerability, one that emerges with life itself." Instead of understanding vulnerability as a *result* of the relationality of the human being (as seen in the case of Feenberg's dependent body), for Butler vulnerability is an *ontological*

[164] Retrieved from https://www.merriam-webster.com/dictionary/patient.

human state, "a condition of being laid bare from the start and with which we cannot argue" (Butler 2004: 31). In a similar fashion, social scientist Tiina Vaittinen (2015: 104) writes that the human body is "internally and persistently vulnerable to life itself: to aging and decay and, ultimately, to death. This corporeal vulnerability is part and parcel of our very embodiment, and there is nothing dramatic about it. It is just life."[165]

The following story by Heidi illuminates well the vulnerability of the dependent body. This account was told to me in our first actual meeting at the hospice ward, when, as usual, I had initiated the conversation by asking a little bit about her background, how the diagnosis was discovered, and so forth. Heidi embarked by telling me her story. At some point in the diagnosis process, a colonoscopy was necessary in order to determine what was wrong with her. By this time, Heidi had been suffering from severe abdominal pains and had difficulty defecating. She shared that she had needed to go to the toilet up to 70 times a day, and naturally she was very sore. She was told that the colonoscopy would last about half an hour. Because of her pain, Heidi asked about the possibility of some kind of anesthesia. The healthcare practitioner answered that the procedure was usually done without anesthetics. Heidi surrendered to what needed to be done, thinking, "You do as it best suits you." Heidi did not want to make a fuss about it, she said. In the end, however, it took an hour and forty-five minutes to complete the whole colonoscopy. "An hour and forty-five!" Heidi repeated, "And then they even changed doctors while doing it. And all that without any medication. That was like…" At this point, Heidi started breathing heavily: "It was so excruciating… It was not fun. Afterwards, everybody had already left. Even the cleaners had left, except for one cleaner who was waiting…" For a moment, I could not make sense of Heidi's words but then she continued, telling me that the cleaner had made some comment about her sitting there on the toilet seat. Heidi could not talk anymore; she was just crying silently. (Heidi/1.)

The procedure had been traumatic, but the result made the situation even worse, a large malignant tumor. Heidi got emotional when she described to me how the doctor had shown the tumor on the screen: "I can still see it in front of my eyes… that thing… inside of me… It was sixteen centimeters long. I knew at once that this was it." Heidi had done her Googling by then, having already suspected the worst. Nonetheless, it was a great shock. (Heidi/1.)

Heidi's experience was extreme in many ways. Her cancer turned out to be very serious and already very progressed once it was found, and indeed the colonoscopy was a necessary diagnostic tool to find it. Medically speaking, the procedure was required. The use of two different doctors also suggests that the examination was challenging. Yet none of this lessens the meaningfulness of Heidi's own subjective experience of the situation. The fact that she did not ask for analgesics *during* the procedure after it turned out to take longer than anticipated

[165] Vaittinen (2015) notes that in modern times, notions of the body and vulnerability have been largely excluded from political discourse as they oppose the political ideal of the autonomous subject. Simultaneously, the vulnerable body is easily seen as effeminate, whereas the autonomous political subject continues to be associated with masculinity, which has led to a conception of the vulnerable body as an apolitical body.

even though she clearly suffered from the pain shows how difficult it can be for a dependent body to reclaim agency.

I would also draw attention to the technologically mediated state of being in the situation described by Heidi. In this particular colonoscopy, the patient was laying on her left side, naked from the waist down, with the doctor(s) and nurse(s) behind her. A flexible tube, a colonoscope, was inserted into the rectal cavity in order to project the interior of the colon onto a screen via a tiny video camera. The live image of the colon, now showing on the computer screen, became the object of the medical gaze. Heidi's existence was mediated jointly via her own body and the technology, which in that moment had become part of her. The patient's being was simultaneously both dissected and distanced, as well as invaded and magnified with the digitalized imaging technique and medical machinery of the colonoscopy.

As we have seen, for patients, technological agencies can have multiple effects. Some are empowering and enabling, whereas others can be disempowering, at times even humiliating.[166] Reconciliation of the patient's subjective needs and the prerequisites of the medical technologies may be very challenging at times. It might be that in some situations it is not even possible. What becomes obvious from Heidi's account, however, is that a *dependent body is always a vulnerable body* entangled in complex material relationalities fueled with *potentia* and *potestas*.

This memory that Heidi shared with me was part of her illness trajectory. It was probably also painful because it marked the moment when her life's landscape changed dramatically. As I have explained earlier, Heidi had postponed her initial visit to the doctor for a very long time. Although explicitly Heidi denied any sentiments of regret, I quietly suspected that part of her pain was traceable to this issue. Still, Heidi was the one research participant who compared our discussion to a religious ritual. After we had had our conversation and we were stopping the interview, Heidi's eyes lit up and she said: "Wow! That was a good experience. Somehow so purifying… It was like some sort of religious ritual!" (D1: 104). It sounded that the act of talking about her difficult memories gave her some relief.

[166] A recent study on emotional predictors on bowel screening shows that many patients experience fear, embarrassment, and disgust to such a degree that it may cause avoidance of the procedure (Reynolds et al. 2018). In regard to women's pelvic examinations, apart from physical discomfort, patients have reported experiencing feelings of shame, fear, and humiliation (see Yanikkerem et al. 2009).

8. LEARNING TO DIE IN THE HOSPICE HOME

8.1 Encountering the hospice home

The day hospice

When I visited the day hospice for the first time, I was surprised by the uneventfulness of the program, even though I had been kind of warned about this before starting my fieldwork. Prior to starting the fieldwork, I asked the chief doctor of the hospice what usually happened at the day hospice, and they had bluntly replied to me, "Nothing." This is what I also thought at first, but after spending some months at meetings and following various patients, my understanding of the day hospice changed considerably.

The morning started when the driver of the hospice home brought the "Tuesday crew" to the facility with his special van, which was equipped for wheelchairs and so forth. With time, I learned that these morning encounters with the driver were already meaningful: during the drive patients exchanged their latest news with him. When the van arrived in front of the main door, the day hospice staff (including me, when I was visiting) would go to the hall to greet all the patients. Each patient was welcomed with a hug by the staff and volunteer(s). The day hospice team was comprised of two nurses, and one or two volunteers who regularly assisted with the daily practical arrangements, such as serving food and making the table ready.

The welcome hug was a clear ritual that reflected the hospice ethos. One Tuesday there was norovirus going around the ward, so physical contact was not recommended. The staff introduced a substitute for hugs, a greeting ritual in sign language of crossing one's arms over one's chest and smiling at the other. If the hugging ritual had not played an important role, creating an alternative would not have been necessary. Indeed, the welcome hug sought to embody one of the core values in hospice philosophy: seeing—and thus validating—the whole person rather than just the patient.

After settling in, everybody enjoyed a small breakfast together (a cup of coffee, a homemade bun, or a bowl of porridge) while sitting together by the big dining table, which filled the main part of the day hospice room. Everyone—patients and staff members alike, including the driver and I—sat together, exchanging the latest news. The nurse kindly but matter-of-factly asked everyone about their health and condition, and the following discussion tended to revolve around the latest development of the illnesses and their various physical symptoms. I was somewhat surprised about the directness of the communication, but this was perhaps an intentional way to dispel any possible awkwardness or embarrassment related to various aspects of the patients' illnesses and symptoms. Although I never heard anybody ever commenting on it, sometimes it struck me how openly various medical details were expected to be discussed (for instance, specific symptoms or various physiological aspects of the illnesses). I wondered if anyone ever felt appalled by this. When I asked about people's reactions to the day hospice

in general, I was told that occasionally someone left the group, because seeing all the sick patients was "too depressing" (D1: 31).

Even with this "permission to be weak," most of the time patients held themselves together remarkably well throughout the day. At times, however, when a patient received bad news about their situation, the pain was just too much (be it physical or spiritual), or if they were simply too tired from it all, they would break down in tears. These moments revealed a sense of helplessness that affected everyone in the room. Most strikingly, it touched the other patients, who perhaps recognized similar feelings in themselves.

Every Tuesday the nurse made sure that she spent a private moment with each of the patients, thus guaranteeing that there was proper space and time for an intimate, one-on-one conversation. In this way, patients were able to voice their worries and questions, and when needed the nurse would consult the other nurse or call the doctor for help. She checked everybody's medication and made sure that each of the patients had everything under control for the week to come; any possible appointments with a social worker, physiotherapist, or oncologist, or visits to laboratories, X-rays, and so forth were talked about and confirmed. The nurse served as a mental and social support person, as well as a kind of outsourced memory aid for the patients.

After breakfast, some went for a cigarette while others retired to comfortable armchairs and a sofa located by large windows. When it was winter, it was customary to check the weather and to follow the little birds flying in and out of the bushes outside. There were daily newspapers on the coffee table, and often the talk followed current news. The topics could be anything, ranging from the most mundane everyday issues to cultural and political analysis of recent events. Books were one of the most popular topics of conversation, reflecting a reading hobby shared by some staff members and several patients. Books and their authors were discussed, and books were also exchanged and loaned. If someone had been traveling abroad (often it was one of the volunteers), it was a shared pleasure to hear of their trip and perhaps see some photos. Symptoms and various issues related to the patients' illnesses often came up, the latest laboratory results were exchanged, and news on tumor imaging and so forth were shared. It was very notable, however, that even if sickness and all sorts of medical issues were discussed regularly, death and dying were rarely mentioned. In general, everyone shared whatever they felt like sharing, but it was also perfectly fine to withdraw into a more quiet space and just passively follow the conversation.

Research participants such as Aili and Inkeri commented to me how meaningful these moments of sharing were. I understood this to be partially because of the physically limited life that many were forced to lead. Even if travel was physically still possible, sickness often caused a serious decline in a patient's income, and economic limitations made any extra expenses impossible for many. Hearing stories by others opened windows onto worlds that were off-limits to many patients in their current life situation. Aili talked about this often; she mentioned

a number of times how much she enjoyed hearing people tell about their lives, families, travels, and experiences (D4: 16). Aili was also an avid reader and she repeated time after time, "Books have kept me alive" (D2: 30, 79). Especially after needing to give up her community garden, books and reading occupied Aili's days (see more in Chapter 10).

One of the major rituals during the morning hours was Bella's visit. Bella was a big and lively rough collie with a red scarf around her neck. Her master Patrick brought Bella to the hospice every Tuesday since his daughter's death in the early 2010s. Patrick kept returning, hoping that Bella might bring some joy to some patients. For the Tuesday crew, Bella had become an essential part of the day's program; she was a much-awaited guest for whom the "dog persons" kept special treats in their bags.

Food and common shared meals were an essential part of the day. The day hospice was arranged around three different meals that were served there: breakfast upon arrival, lunch at noon, and afternoon coffee around 2 pm before the ride back home. At lunch, everyone gathered around the big table again and shared the meal. I often heard patients wondering how food tasted so much better when it was enjoyed together. I also noticed the staff members discreetly following how everyone was doing with their meals. A healthy appetite or complete lack of one could reveal things about a patient's physical—and mental—state.

After lunch, some patients went for a little rest in the side room, where there were two beds for the use of the day hospice. Some made a little walk around the hospice home and sat for a moment in the winter garden, or they went outside if the weather permitted. Somebody might have medical foot care or a hairdresser at the neighboring nursing home, and sometimes a masseuse would give a patient a special treatment.[167] Occasionally a singer and music therapist would visit the group. A couple times per year, the day hospice organized a little excursion, for instance, to a nearby park. These were luxurious additions to otherwise ordinary days, and they were much appreciated by everyone.

Day hospice in general gave an impression of a free and patient-centered space. The hospice home, however, is an institutional place with its own ritualizations seeking to structure and striate time and space. If in medical rituals (such as diagnostics and treatments) the issue of power becomes tangible in the manipulation of the body, in other types of institutional practices and rituals the power practices can be more subtle (even if they continue to manipulate the body). Here is a description from my field diary:

> I had suggested to the Tuesday crew that everyone could bring with them some photos to share with the group. After the breakfast Rauha stayed at the dining table, with a face like "aren't we gonna look at the photos now?" I gently asked the others if they had brought any photos. Soon everybody joined the table, and they all looked really interested, even those ones who had no photos with them. […] At one point, we—all women—started talking about babies and birthing. It was an unexpected moment; the atmosphere became intense and intimate. We were right in the

[167] Often times such extra services were given on a volunteer basis or, in the case of masseuses, with the aid of a specifically assigned donation.

> middle of it when we were suddenly interrupted. There was some other program planned for the group. We needed to get up and leave right away. (D4: 8)

The ritualized moment to look at photos,[168] which had created an unforeseen space for deep conversation, was brought to a halt without advance warning. The institutional space of hospice was seemingly smooth and loosely structured, but in reality, like any institution, it was still structured and ritualized—and even contested at moments. I learned rather quickly that the day rhythm was carefully laid out, and any external or additional program that threatened the usual schedule was not necessarily welcomed. Furthermore, certain activities seemed more important than others; for instance, a medical procedure—such as measuring blood pressure—seemed to have priority over a conversation (D1: 13; D4: 9). If hospice smooths the striations of the hospital, there are always some institutional elements which seek to striate the hospice.

Ritualization of the ordinariness

Ordinariness and uneventfulness were features that made the time spent in day hospice so valuable for many of the patients. It took me a while to reach this conclusion, for at first I found the "nothingness" merely dull and boring, and I assumed that the patients would agree. After talking about this discreetly with some of the research participants, one or two indeed expressed eagerness for more "program" (D4: 6), but in the end, after having followed different patients for years, I came to understand that the uneventfulness was actually gratifying and soothing for most of them. Ordinary, everyday things, which had previously been taken for granted, had now become a valuable rarity for them.

This is understandable when considering the general trajectory of illness. When the terminal illness advanced, there tended to be more kinds of symptoms (e.g., pain, nausea, dizziness, insomnia, severe constipation or constant diarrhea, neuropathy, breathlessness).[169] When the physical capacity to live diminished and symptoms shadowed daily life, many expressed missing most "the little things of ordinary life," such as being able to enjoy one's meal, going for a walk, or even just being outside and feeling the wind in one's face. In this light, the statement "the hospice home is the safest place to come to" becomes more nuanced. Existential insecurity and fear of the coming death became constant partners for the patients—even if they were not explicitly spoken about aloud. This is what sociologist Arthur W. Frank (2001: 355) refers to when he writes about suffering with no words: "Suffering is the unspeakable, as opposed to what can be spoken; it is what remains concealed, impossible to reveal; it remains in darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful."

When ordinary everyday life becomes scarcity and the small daily details of life are no longer self-evident, they may gain importance beyond the trivial. Details matter in a new way, and old

[168] See Quartier 2010 on looking at photos as a modern deathbed ritual.
[169] To make it clear, I am not offering any estimations about the possible prevalence of any symptom in particular; instead, I am merely referring to the experiences of my research participants, who do not represent a statistic sample population.

everyday routines may become ritualized, as they remind of life as it used to be, that is, life without the threat of imminent death.[170] While food and eating *per se* may already be ritualized (Marshall 2005), food can gain additional significance and connotations after one becomes ill (McInerney 1992; Ellis 2018). Some of my research patients told me about ritualized gatherings around food—explicitly relating to farewells. Soon after Eeva received her terminal prognosis, she invited her best friends to her house for a meal. She cooked them a traditional Finnish meal and for desert they enjoyed some cake. "We settled around the meal," she described the farewells to me (D1: 77–78). Inkeri, on the other hand, organized special meals with her friends and family only a few days before she died (Inkeri/4). In addition to the meals, Inkeri had made a special gift infused with memories of their friendship, and she had decorated the table with some pictures and items from their common journey. "All the decorations and the food, it somehow embodied and brought to life our years-long friendship and the connection between us," she described. "It was a big fulfilment to say goodbye to the best friend… there was a sense of farewell there" (Inkeri/4).

In the day hospice, the moments of gathering to eat were ritualized through a myriad of small gestures, mostly initiated by the staff yet happily joined in by the patients. One ritualization started with the setting of the table. In addition to the usual plates and silverware, the setting was characterized with specially folded napkins, usually done by one of the volunteers. Soon the folding art became a topic of conversation and source of common admiration, as patients started paying attention to the different styles and attempted themselves to learn new ways of folding. Some patients did not even wish to use the napkin but slipped it into their bag instead.

Another feature underlying the ritualization was the timing. It was remarkable how exact the schedule for the lunch was. Even if patients were engaged in deep conversation, which could appear to be emotionally significant, "the invitation" to the table was firm. This caused a sense of irritation at moments, and it forced me to reflect on why it was so important to follow the schedule so precisely. In addition to the obvious "let's eat when the food is warm" logic (which was not the common practice elsewhere in the hospice home, such as on the ward, where eating happened depending on the patient's wishes and needs), I believe that the gatherings around the table structured the day and the group in a necessary way. In terms of striated and smooth space, in general, being in day hospice was free and loose—manifesting smooth space; conversely, the strict eating hour created coherence, not only for the time spent together but also the group overall. It was a gesture of striation by the staff to organize time and space in this manner. This was the only moment that everybody from the group was together, whereas at other times of the day people could withdraw in smaller groups into different areas to chat or even to be alone.

In general, food symbolizes life; it gives us energy and provides continuity (Marshall 2005). Eating together and sharing meals comprise perhaps the most ancient ritual of all—the Last

[170] The importance of small everyday gestures was recently brought up in a French study on a palliative care unit, which showed how seemingly banal and insignificant expressions become meaningful in palliative care (Drillaud et al. 2020).

Supper and Thanksgiving dinner are classic examples (Mintz & Du Bois 2002). Furthermore, food represents connection and interrelatedness in multiple ways, including an embodied connection with the earth (and various lifeforms in the world) where the food comes from and a social connection with the others with whom one shares the meal. A common comment heard at the food table was that eating was essentially different when shared and done together. It can be said that sharing a meal embodies one of the most basic and common rites marking social inclusion and exclusion in communities. Therefore, if suffering, as Frank (2001: 355) states, is essentially about disconnection, about an absence and experience of oneself "on the other side of life as it should be," then sharing a meal functions as a kind of antidote for suffering, as it is all about connecting and relating.

Day hospice exemplified other types of connection as well. Many hospice and palliative patients live in some form of exclusion due to their physical, psychological, and (often) economic situations. A couple of my research patients (Kimmo in D1: 74; Helena/1) remarked on how little public talk there was about the economic strain of a serious illness. In some families the level of income crashed, affecting the daily life of the whole family. Poverty or low income in itself may be a causal effect for social isolation and the sense of belonging (Stewart et al. 2009; Eckhard 2018).[171] Furthermore, low income and a life-threatening illness together can lead to serious loneliness. This can be alleviated by common meeting places, such as the day hospice, which offered patients moments *to relate to and to feel related to* the outside world. It was a chance to "be taken care of," to relax, to seek information from the specialists, and to chat with peers—all in a safe environment.

The presence of the volunteers in the hospice home made it easier to create the atmosphere of "everyday life," as there was nearly always someone to talk to—not a fellow patient or staff member but just an "ordinary person" representing "ordinary life." Chatting with volunteers brought a fresh breeze of the outside world and a little change of scenery to the patients, as Aili remarked to me many times. Ordinary life is about movement—in contrast to the sedentary life of illness—and day hospice offered a window onto a mode of being that was no longer available to patients. This, in turn, facilitated an atmosphere of hope.

8.2 The smoothing presence of death

When death sneaks into words

It surprised me how little talk there was about death and dying in the day hospice.[172] After all, that was the common denominator for everyone to be there, with the exception of the staff and volunteers. Aili (D4: 14–15) once commented on this phenomenon as well. She believed it was

[171] This was discussed widely in Finland in autumn 2018, when *Helsingin Sanomat*, the country's largest newspaper, published a large survey based on letters by the public on the subject of poverty, including its consequences in people's lives (HS 2019).

[172] Utriainen (1999: 189–190) also remarked on the invisibility of the death in the hospice home where she did her ethnography; death and dying were segregated even within the hospice space.

actually a good thing that there was not so much talk about death and dying, for otherwise there would be a need to have all kinds of discussions about the afterlife and, consequently, about religious matters. For Aili, that kind of thing felt awkward. Even though Aili respected the Lutheran Church, she was not religious; this came out in her way of talking about the Church, but she also directly said it to me (Aili/2). She did not believe in the afterlife; instead, she talked about her "cells dying and then going to cycle around" (Aili/2). She expressed to me that sometimes she felt like she needed to censor what she said in the day hospice, as there were some people who were more religious than her, and she did not wish to offend anybody with her views (D4: 14–15).

Even if it was not explicitly talked about, the thought of death was still present. According to Aili, "it [the thought of death] is in the back of everyone's mind and *we share it by not talking about it*" (D4: 17). I remember some isolated incidents in the day hospice group when we were all talking something about the hospice home and then someone blurted out something like "Well, that's why we're all here, that we…" The person never finished their sentence, and it was just left hanging. Death was not often talked about, and for the most part it was not seen either, but occasionally it still sneaked into the day hospice conversations.

After I had been part of the Tuesday crew for a little more than three months, one of the original members of the group, a very elderly lady called Irma, was taken to the hospice ward because her condition was deteriorating. The group continued to gather on Tuesdays, and someone always went to visit Irma in her room. This was followed by subdued talk about her condition among the day group. One particular Tuesday, Siru came back from Irma's room and told everyone: "Irma was very tired. She had had a very bad night, lots of pains… She is totally ready to go." Someone commented: "Yeah, she has talked about it even publicly that she is ready to leave from here" (D1: 24). Irma was caught in the middle of living and dying. Humorously, she had even commented on her lunch by saying that "the food tastes so good while waiting for death!" (D1: 28).

About a month later, when Irma was still on the ward, a new member named Taina had joined the Tuesday group. Siru visited Irma again, and upon returning to the day hospice room she repeated Irma's wish with some anguish in her voice: "She *really* would like to leave already!" As Taina did not know Irma, she unthinkingly assumed, "Ah, I see, she would like to go back home already." Siru looked perplexed as she corrected Taina, "No… I mean, she would like to… like to *sleep away entirely*." After Siru carefully uttered these words, an awkward silence fell in the room. Taina seemed sincerely surprised by what Siru had said, as if taken aback that someone was actually dying in the hospice home. I could not help the impression that she had not really grasped where she was.[173] (D1: 32.)

[173] After I got to know Taina better, I understood that she lived her end of life very actively and never really conformed to the role of a dying patient.

It took another two weeks before Irma finally died. Since her death happened the night before the Tuesday meeting, the following morning everybody in the day hospice was talking about her passing. Irma's daughter came to thank the Tuesday crew, and there was almost "a satisfied humming," as I wrote in my diary, about the fact that Irma had finally "departed" (D1: 33). Everyone was saying "she was *so* ready to go!" Referring to her actual dying, someone even remarked, "It went on a bit too long" (D1: 33). It seemed like there was an unspoken but common perception of an *ideal timing for death*, as it was unanimously agreed that Irma's waiting had simply gone overtime; it had taken too long.

This was also one of the rare occasions in which I heard patients talking about euthanasia.[174] Toward the end of the day, people once more started to talk about Irma's death. Again, as if to affirm that it was a good thing that she had died, it was repeated how much she had "wanted to go," and that "actually she had been wanting that already for two months!" In the midst of the discussion, someone started pondering: "I wonder if one can affect that [the timing of death]." The conversation shifted to focus on this question. Someone answered, "I don't know," and another one added, "I suppose not." Finally, somebody engaged the topic: "It is uncanny that even if one *wants* [to pass] away, there is no way to effect that. One cannot really oneself effect that at all." Another patient nodded: "Yes, here I can understand the positive viewpoint on euthanasia." Others joined the discussion with approving tones: "Yeah, if one *wants* to go!" In the end, someone revealed that Irma had actually asked her daughter to give her "some kind of an injection," to which the daughter had only answered, "Oh mom, I wish I could!" This in turn prompted Taina to ask, "Yes, why not? We help suffering animals, don't we? We put an end to their sufferings if there is no more sense in anything…" (D1: 34).

This conversation gave me the impetus to ask later on from the staff if this sort of talk was common among patients, and if anybody had ever actually requested euthanasia.[175] One of the nurses who had worked in the hospice home for decades told me that such talk was infrequent, and it was rare to hear concrete requests about euthanasia. "It is almost surprising," she thought, "given the condition of some" (D1: 34–35). The nurse did acknowledge that especially when the patient's condition rapidly worsens and they become immobile, it is not uncommon to hear wishes like "Oh, I wish I would get away already," yet she firmly believed that this was not a *genuine* death wish but rather a somber expression of feelings of despair or shame, perhaps, or a fear of becoming helpless and being in need of constant assistance. The nurse asserted that these feelings subside after some time.

[174] There were two other moments during my fieldwork when the issue of euthanasia naturally arose. The first happened with Pekka, who told me that he had thought of euthanasia but since it was not possible in Finland he had "prepared himself" (Pekka/1). He never did anything for real, but apparently he had made preparations for taking his own life; I heard that he had kept an "injection" for this purpose. Another discussion about euthanasia was with Aili, who talked about it on the basis of her professional and personal experiences around death. She believed that it should be allowed in certain situations. (Aili/2)

[175] It should be noted that around this time, the topic of euthanasia was very much discussed in the Finnish media, and there was an organized citizens' initiative for its legalization. The initiative officially started collecting names in 2016, and it was brought to Parliament in 2017. The proposal was never approved, however.

Irma's death was the first shared death experience in the Tuesday group when I was there. It was meaningful for everyone. It opened up—and even forced—the space to encounter the salient mortality that was silently present everywhere in the hospice home. A week later, when we gathered again with the group, there was a need to bring some positive closure to Irma's passing. Siru commented on her death by noting what a beautiful smile Irma had had on her face after her death. "She must have met her late husband," Siru murmured, "she looked so young and beautiful, all the wrinkles were gone!" After this, Siru repeated how good it was that "she finally got away, as she wanted it so badly." Others mostly remained silent, but confirmed that Irma's smile had always been very beautiful indeed. (D1: 38.)

Smoothings and striations at the hospice home

Whether death was spoken or unspoken, visible or invisible, it surely formed a major part of the hospice home's daily reality. A concrete reminder of this came one afternoon during the coffee hour. We were all sitting by the dining table when through the glass windows to the corridor we saw two staff members pushing a bed with somebody on it. We knew that it was a corpse, as a sheet covered the body from the top of the head to the feet. The conversation and all motion around the table abruptly stopped. In solemn silence, our eyes followed the cadaver's passage toward the chapel where bodies were kept in cold storage before transfer to the funeral home. Even with the sheet, we could see that the body was being pushed feet first, following custom. One foot poked out with a colorful, homemade wool sock. Instantaneously, at the sight of something so ordinary and familiar, the anonymous body was transformed into a person—perhaps someone we knew, a friend even. After we lost sight of the passing bed, someone broke the silence by saying: "That surely gives pause…" The coffee hour continued in pensive silence, exactly as Aili had framed it: the thought of death was shared by everyone—in silence.

From a Deleuzoguattarian point of view, these sorts of small interruptions smoothed the striated space of orderly routines and ritualized practices around which any institution, including the hospice home, revolves. In the hospice environment, this kind of smoothing was tolerated and allowed, and even invited sometimes. Smoothing effects can be even called for by spatial arrangements, such as (wild) gardens, and by facilitating loosely organized events like parties (such as birthdays or even marriages). In these spaces and moments, life and death are allowed to happen in a less controlled manner.

On the other hand, there were small ritualizations at the hospice home which worked in a striating manner to counter the intimidating effect of the smoothing. When the patients in the Tuesday crew started to form friendships with each other and inter-group cohesion grew, the nurse took the initiative to commemorate the passing of the members by lighting a candle on the dining table during the afternoon coffee. "For the memory of Irma," she would say, lighting the candle. There was no need for any further ritual; in its simplicity, the lit candle fulfilled the purpose. By having the candle on the dining table, it was as if the dead person was present with the group. In addition to commemoration, this practice worked as a gentle but effective

reminder to everyone about their own coming death. Furthermore, lighting a candle was already an existing part of the hospice home's rituals: a candle was lit in the lounge every time someone passed on the ward.

Although rather minor in itself, this gesture was one among many in the hospice home which essentially reflected awareness about mortality. Even if death was not necessarily talked about out loud, there was nonetheless a possibility for pondering death and dying, which happened discreetly via these small ritualizations and reminders.

PART IV – PERSONAL RITUALS AND AESTHETICS

In the last part of my analysis, I will move from institutional rituals to an exploration of the personal rituals practiced by my research participants. Personal rituals in this regard may be divided between ones that seek to avoid death and dying and ones that clearly prepare the patient for their coming death. In addition, some ritualized practices, such as writing, may push the thought of death further out onto the horizon while simultaneously preparing the writer for the inevitable. Following Kapferer's interpretation of virtuality, I will look at these practices as creations of ritual virtuality, which offer participants possibilities to reorient and learn new ways to handle their situation. Furthermore, various personal rituals can be seen as ways to enhance one's own agency over the challenging existential situation.

Rituals and other participatory practices, especially those involving nature and the arts, can prove to be important channels for augmenting potentiality and thereby increasing Spinozian joy. The latter half of Part IV thus concentrates on various sorts of participatory practices, such as religion and aesthetics, in relation to approaching death. In particular, I examine the role of aesthetics as a significant tool for my research participants in their process of seeking to understand and come to terms with their existential situation. To this end, I elaborate on the way in which aesthetics can offer therapeutic tools for handling the crisis caused by terminal prognosis and, furthermore, I show how aesthetics permits but does not force metaphysical imagination and meaning-making.

9. PERSONAL RITUALS

9.1 Rituals for avoidance of death

Enhancing life and the body

When the thought of death or the idea of one's tangible dying was something too difficult to grasp, patients engaged in numerous small ritualizations and actual rituals, which helped them to reinforce their ties with life, and thus avoid (the thought of) death. Like we can see in the following quote from my research diary, these activities often focused on the very physical and concrete *premises of life*. This is what I had written in my diary about my mother:

> Soon after mother had received the news [about her terminal cancer], the first thing she did was to buy an enormous amount of outdoor plants. There were pots on the ground and pots hanging from the edge of the roof, blooming flowers everywhere in the yard. Living flowers which needed attending care. Upon hearing the terminal news, she needed to nurture life and beauty. (D4: 10)

These ritualizations and rituals were built upon various *life-strengthening* acts, elements, or symbols that aimed to reinforce connections to life in a physical, social, or more abstract sense. They functioned as consolidating one's subjectivity and one's relations to the world—hence, these sort of ritualizations can be also called "rituals for avoidance of death." This does not mean that patients were always engaged in them by thinking consciously or unconsciously that they would actually escape their death; rather, at times these ritualizations were simply expressing one's aspiration to immerse with life (as contrasted with death). At other times, these rituals seemed to reflect certain beliefs, such as "as long as I eat I cannot die" or "as long as I continue physical exercise, my body will stay strong and I cannot die." In general, I interpret these personal ritual practices as a participatory mode of being, in contrast to the causal orientation to reality perhaps best described in terms of medicine and medical rituals.

Many of these participatory rituals revolved around the body. Whether that meant doing sports or applying make-up, they served as a kind of *antidote for the threatening disintegration* brought on by terminal illness. As mentioned earlier, Kimmo, for instance, believed that if he kept on eating healthily and continued to work out, his body simply could not fail him and he would not die. In one way, of course, Kimmo accepted the fact that he *might* die, and he had taken care of practical matters like organizing his economic reality (e.g., banking, insurance papers) and transferring things over to his wife (D1: 74). On the other hand, he had a hard time believing that he was *actually* dying. The whole time I knew him—the last three months of his life—it became very clear that instead of looking at death, his eyes were set on life and on the idea of recovery. Accordingly, he was convinced of the importance of self-care (D1: 118–119, 122). When on the hospice ward, he ate substantial portions of food. This was striking, since often my research participants—even when they were taking cortisone, which enhances appetite—clearly ate less than normal (see also Orell-Kotikangas 2015). Kimmo commented on this a few times by stating that he was trying to regain his stamina and physical energy, and

that he believed it was important to eat well to recover. As noted above, Kimmo applied himself to physical exercise with similar devotion. Even when on the hospice ward, he did rounds with his walker, in order to stay fit. After he went into home care, he kept going to the gym, despite warnings by the medical staff. He believed that by exercising he would regain his strength and thereby recover (D1: 109, 122).

Physical exercise and various sorts of bodily activities came up regularly in the discussions with patients. Among others, Oiva, Aili, Kimmo, Matti, Helena, and Heidi talked about how they had enjoyed various bodily activities, and hence a certain sense of freedom, prior to their illnesses. Embodied living in the form of such hobbies as sailing, having a summerhouse, gardening, running, swimming, and skiing had positively affected many by bringing them (Spinozian) joy; it had increased their quality of life by begetting a sense of strength and increased capacity of movement and life (D1: 8, 72–74; D2: 6–7; Matti/1).

My mother also believed that as long as one kept oneself "physically together," everything was all right. She believed that it was important to get up out of bed every morning, dress nicely, and apply some make-up—in other words, keep her physical appearance under control. Giddens' notion of the "regularized control of the body" is helpful here; it illuminates well how crucial control of the body became for some of the patients. It was through these small everyday ritualizations (i.e., Giddens' regularized control) that some patients sought to keep their "biography of self-identity" coherent, and thus kept the ontological insecurity at bay (Giddens [1991] 2006: 56–65).

Whether the enhancement of the body relates to the need to sustain bodily coherence, achieve a feeling that one is "at least trying," or combat the experience of hopelessness after the medical treatments had failed to improve the situation, the market has recognized a niche here. Kimmo told me that once when he was at the hospital, a man poked his head in the doorway and asked him to come out of the room into the corridor—apparently the hospital had banned this individual from entering patients' rooms. When they were standing in the corridor, the man told Kimmo that even if the doctors offered him no more hope, the situation was not doomed. Just like a certain well-known Finnish artist, the man had explained, Kimmo could also be cured with alternative medicine that used mistletoe as its main ingredient (D1: 83). When Kimmo told me about this, he seemed simultaneously amused about the range of possible therapies but also somewhat upset about those taking advantage of patients' despair. Even if Kimmo did not seem to believe in the mistletoe, he had nevertheless saved and kept the leaflet.

The body as the site of virtuality

Attempting to maintain the self-identity as coherent in order to enhance ontological security is one way to approach the small ritualizations of consuming special foods, supplements, and so

forth. Yet another perspective is offered by Kapferer's (2004, 2006, 2010) theorization on ritual virtuality,[176] which complements the interpretation of rituals as participatory modes of action.

Discussing Bruce Kapferer's virtuality in regard to time, anthropologist Don Handelman (2013: 36) describes how ritual virtuality is engendered by concentrating on the "continuous present" or "presentness of the present." which slows down the flow of time by intensifying it. According to Handelman, this is the space in which rituals happen. One way to create—or to enhance—the presentness of the present is to immerse in bodily sensations and relational kinesthetic experiences. This is largely what happens in many rituals, including the embodied practices that my research participants engaged in.

Kapferer bases his understanding of the virtual on the philosophy of Susanne Langer and, in particular, Deleuze and Guattari. Although Langer's and Deleuze and Guattari's notions of virtuality differ in many ways, they share the understanding that the virtual is essentially a *dimension of the real*.[177] In other words, the virtual is understood to be no less real than what the actual is; rather, actuality and virtuality are both facets of reality yet different.[178] Furthermore, the virtual dimension of the real is vital for actuality, because of the potentialities that virtuality holds. In other words, the virtual precedes possibility; it can be seen as creating the conditions for possibility.[179]

Kapferer (2004, 2006) sees ritual as one kind of virtual reality in which ritual participants can *seek to enhance their potentialities, invite change upon themselves, or practice new solutions and change*. Kapferer (2006: 673) calls the virtual of ritual a kind of "phantasmagoric space" that "allows all kinds of potentialities of human experience to take shape." It is at once a construction, a self-contained imaginal space, but simultaneously a construction that "enables participants to break free from the constraints or determinations of everyday life" (Kapferer 2006: 673).

Applying this theory to the rituals of make-up and physical exercise, I would argue that here the body itself becomes a *locus of the virtual of ritual*. By enhancing one's (dying and

[176] Kapferer (1997, 2004, 2006) applies the notion of virtuality to a rather "conventional ritual" (in an anthropological sense). He is critical toward Bell's understanding of ritual; according to him, her theorizations borrow too much from theories that do not relate to rituals at all (e.g., Bourdieu's (1991) practice theory; Kapferer 2004: 36–37). Despite this, I am convinced of the usefulness of his idea of virtuality for my study, even if I apply it here to not-so-conventionally defined rituals, which are plentiful in my ethnography.

[177] One way to think of the relationship between the actual and the virtual is to see how "scientific technology creates a virtual opening in actuality" (Kapferer 2006: 675). For instance, an MRI is able to illuminate an aspect of actual reality which otherwise might not be grasped. Actuality is available to representations but "in excess of any attempt to represent it" (Kapferer 2006: 676). However, via the help of scientific technologies, we can "descend into actuality within which certain dimensions of the chaotic flux of actuality are suspended or slowed down—the virtualizing process—so as to facilitate the examination and manipulation of aspects of actuality" (Kapferer 2006: 675).

[178] The relationship and possible subordination of the actual and the virtual differ among the various readers of Deleuze, and Handelman's view on this differs from Kapferer's understanding (see Handelman 2013). I need to leave out the philosophical fine-tuning and further speculation on these here, since my primary aim is to offer concepts that can illuminate my ethnography (not vice versa). I take the liberty to enlighten them only as much as needed for my analysis.

[179] This reading of virtuality also echoes Utriainen's understanding of the ritual subjunctive (2016, 2020).

weakening) body with aesthetics of vitality and youth—both being apparent features in make-up and fitness imaginaries—the dying subject is inventing and inviting more potentialities for themselves. The body becomes the point of an embodied aesthetic experiment, a ritual site in itself, in which—and for which—one seeks to create new possibilities of life. This is done by invoking the lost vitality or fitness, applying and implementing those symbols and elements of youth, life, and regeneration which our culture recognizes and values, and through them creating the potentiality for strengthening one's life. There is always the possibility that one may not "make it"—in this case, survive cancer—but if one does not even try to create space for the possibility of recovery, possible healing, and vitality, then the likelihood of "losing the battle" is ever greater.

Subjects create the ritual virtuality filled with *potentia* with whatever tools and means there are available in the given cultural context. It may happen via participation in a traditional healing ritual, such as seen among the Sinhalese in Kapferer's study of Sri Lanka, or it may happen via other kinds of ritualizations which invite healing. One may consume mistletoe, apply a strict exercise regime, take medication, or visit a contemporary Western healer.

Ritual virtuality at the healer's house

Similar to Kimmo, some of the other research patients lived the end of their life in an ambiguous state, simultaneously knowing that they were approaching death yet unable to face it. Oiva, for instance, had been seriously ill for about fifteen years, and as a day hospice patient he knew that his death was approaching. Yet, when toward the very end of his life he was admitted to the hospice ward and his organs started to fail, he felt bewilderment and disbelief: "I was prepared that I will die from this, but still… It surprises me how… since I have no pains even…" (Oiva/2). Oiva's body was not in pain—not all dying patients experience it—and this made it harder for him to believe that the end of life could be near. Sometimes this simultaneous "knowing and not knowing" was mixed with strong emotions of fear, and at times, this led to patients engaging in alternative actions. This was the case with Vivian, for example, who refused to listen to the doctors who told her that nothing more could be done about her tumor. Instead, she went to a private hospital to continue her treatments. "I came to the conclusion that I don't want to die yet […] I am not ready to leave… or to die," she explained to me (Vivian/1).

Like many of my research participants, my mother also trusted and believed in medicine, but in the end she unexpectedly turned to an alternative and very unorthodox treatment. After her diagnosis, she received one series of chemotherapy, and when that did not prove effective she subsequently continued with radiation therapy. During the last weeks of her life, the locus of her trust shifted. From a friend she learned about a traditional healer who lived an hour's driving away. At that point the medicine did not offer any further hope (she had not been offered any palliative consultation), and hence there was absolutely "nothing to lose." On the contrary, the healer represented hope. This avenue offered my mother a way to gain some power—or *potentia*—over the situation, for with the healer one could at least invite change. In Kapferer's

words, in the virtual space of ritual (such as with this healer), "participants can reimagine (and redirect and reorient themselves) into the everyday circumstances of life" (Kapferer 2004: 47). For my mother, the healer provided an opportunity to create a new understanding and interpretation of her situation.

I accompanied my mother to meet the healer (D4: 12). I had somewhat mixed feelings about the situation, yet I hoped that the healer would be psychologically skilled and in that way could perhaps relieve my mother's anxiety.[180] Of course, I was also curious to meet the healer because of my academic background; I was keen to see how the healer worked. Finally, if not most importantly, I did not want my mother to go alone, as I did not quite trust her driving anymore.

My mother was not unique in her willingness to try out another kind of treatment than biomedicine, although compared to some other countries Finland seems to rate rather moderately in its use of complementary and alternative therapy (CAM). According to an international study, 27% of all of cancer patients in Finland in 1980–2004 used CAM (Horneber et al. 2012).[181] While a recent study suggests that CAM use has decreased since 2008 in Finland (Vuolanto et al. 2020), it tends to be more prevalent in cases of advanced illness (Truant et al. 2013).[182]

The healer's information on the Google Maps page simply called her a "masseuse," whereas her business card said "healer" (*parantaja*), with no further explanation of her style of healing.[183] According to a recent study conducted in Finland, the most commonly used form of CAM includes various biological therapies, such as herbal remedies and nutritional and dietary supplements (Vuolanto et al. 2020). This was also my ethnographic experience, since most of my research participants were taking at least some type of herbal medicine or vitamin supplement. According to an earlier study published in Finland in 2002, when asked about their reasons for using CAM, most cancer patients reported restoring their hope in the future and doing as much as they could for themselves (Salmenperä 2002). These results reflect a need for

[180] Having worked as a masseuse for the Hospice of Santa Cruz County in California, I knew from my own experience how helpful therapeutic touch could be during the last weeks and days of someone's life. Furthermore, as part of my experience with hospice in the USA, I had met various alternative therapists, many of whom were emotionally skilled in working with people with a high level of stress and trauma.

[181] According to the Finnish Science barometer, 34% of Finns believe that practitioners of alternative medicine possess some skills and knowledge which practitioners of biomedicine do not have. On the other hand, trust in medicine, and especially in cancer studies, is very high among Finns (Tiedebarometri 2019). There is very little studied information about the prevalence and experiences of CAM among cancer patients in Finland (Vuolanto et al. 2018).

[182] Since 2000, around 50% of cancer patients around the world have used complementary and alternative medicine (CAM) at some point in their illness trajectories (Horneber et al. 2012). The differences between the various countries and between different time periods can be great: in general, the use of CAM has increased since 2000 and, especially in North America, various alternative therapies have been very common among cancer patients (Horneber et al. 2012; Salamonsen 2013).

[183] The National Center for Complementary and Alternative Medicine in the USA classifies CAM into five main categories: 1) alternative medical systems, such as traditional Chinese medicine or Ayurveda; 2) mind-body interventions, such as meditation, prayer, healing, or support groups; 3) biologically based therapies, such as herbs, dietary supplements, or vitamins; 4) manipulation and body-based methods, such as massage, chiropractics, or osteopathy; and 5) energy therapies, such as Qi Gong and Reiki (Molassiotis 2005).

self-empowerment and agency practice. Based on my earlier experience in the hospice field, alternative therapies mostly supported the physical, psychological, and emotional wellbeing of patients, in contrast to offering actual cures for diseases. For this reason, I was surprised to learn that this healer explicitly used rhetoric about *curing* rather than *caring*. Truant et al. (2013) confirm, however, that some patients with advanced cancer use CAM to improve their chances for a cure. These patients believe, or hope, that alternative therapies could actually fight against the disease (for instance, by shrinking the tumor and enhancing the body's immune response). For others, the value of alternative and complementary therapies lay in their non-curative benefits, such as improving wellbeing and feeling healthier, promoting relaxation and reducing stress, boosting energy, improving quality of life, and management of symptoms and treatment side effects. Some reported using CAM to address unmet emotional, psychological, and spiritual needs, and also to feel that they had done everything possible to fight their cancer and to improve a sense of control over their illness (Truant et al. 2013). In my mother's case, I could specifically see her need for the latter. Doctors kept telling her that nothing could be done about the tumor, but she felt like she had to do *something*. The need to do something was similarly great among nearly all of the patients I met—this may be one reason why rituals are potentially so significant at the end of one's life. Here the ritual becomes a viable possibility to exercise one's agency.

The healer's office was at her home in the countryside. While my mother entered the treatment room with the healer, I stayed in the waiting room outside. There were binders filled with magazine articles and various testimonials about healings done by this particular healer. I scanned them and was surprised to find that most dealt with very concrete health issues, such as migraines, spinal disc injuries, or nerve damage, which, according to the testimonials, biomedical doctors and conventional physiotherapists had not been able to fix. Unlike I had expected, the testimonials did not talk about psychological, emotional, or spiritual healing.[184]

When my mother came out of the treatment room, she told me that the healer had wished that my mother would have come earlier, since now the situation was very difficult to work with. She had talked about water veins under my parent's house as a likely cause of my mother's condition,[185] and she recommended changing the position of her bed so that the harmful emanations coming from the water would not be so great. When I asked my mother what the actual treatment included, she told me that it had been just like massage. I realized that the "division of labor" between holistic healers and biomedical healers did not fall into the "soft" versus "hard" approach or the psychological (or soul) versus physical (or body) approach. The

[184] Scholars of religion, such as Tuija Hovi (2012) and Outi Pohjanheimo (2018), have pointed out that services of various kinds of spiritual healers are sought after equally in the cases of physical illnesses as in other types of social, psychological, spiritual, or even economic troubles.

[185] Since then I have learned that the folk theory of harmful earth radiation and water veins was very common in Finland around the 1970s, actually dating back to 1932 when Baron Gustav von Pohl claimed in Germany that cancer was caused by harmful earth radiation and water veins underneath people's houses (https://swissharmony.com/what-are-water-veins/research-on-water-veins/).

matter was much more complex than I had envisaged. However, when the phenomenon was approached from the point of view of virtuality, it made more sense. The whole healing ritual appeared as an attempt to build an alternate ontology, a sort of new construction or alternative ordering of reality. When we drove away from the healer's house, I heard my mother saying quietly, as if to herself, that maybe it would work and maybe the tumor would disappear (D2: 62). The *possibility* for a different reality had at least been created—it was there to grasp onto now. It was easier for my mother to dwell in the virtuality of the ritual than in the dreadful unknown of the actuality of her imminent death.

The embodied rituals described up until this point have all been concentrated on the body, but there were also other kinds of ritualizations that were not directly about the body. One of them was about writing.

9.2 Writing as a negotiation about life and death

"Writing for life"

Writing is a testimony on being alive. Two of my research participants, Heikki and Marjo-Riitta, actively maintained blogs, both of which had been started only after learning about their diagnosis.[186] Heikki, who had been encouraged to do it by a friend, told me that writing the blog was one way to learn how to handle the situation, and it was also a good way to keep a record of everything that was happening (Heikki/1). In addition, there was a more societal motivation behind Heikki's writing. Prior to getting ill, he had had some prejudices about the quality of healthcare, but now he wished to share how brilliant Finnish specialized medicine really was. Of course, Heikki added, not all the aspects of the care had been perfect; he wished that some improvement could happen in regard to certain attitudes (Heikki/1). He had noticed, for instance, that an orchiectomy (surgery to remove one or both testicles) was recommended rather routinely to him and offered without much discussion about alternatives. By writing openly about such issues, Heikki wished to support others in a similar situation—and, according to the feedback he had received on his blog, he had succeeded in doing in this.[187]

Heikki began writing his blog (*Sairaan rakas elämä*, "Sick beloved life") when he was first diagnosed in 2014. Since then, he has survived two severe cancers, lymphoma and leukemia, and he still continues the blog (as late as 2019). Creativity had always been part of Heikki's life, yet prior to cancer it had mostly taken the form of visual arts and painting. With blogging, Heikki found the writer in himself. Over the course of time, writing became a sort of "mode of living and a way to process things" (Heikki/3), and even a way to survive:

> Many may wonder about how often I update this blog. Writing anchors me into life. My dad's former neighbor used to do running even though he did not like it *per se*, but he thought it

[186] Since these two blogged publicly with their own names, I refer to them here in that way.
[187] This discussion in the blog led to an invitation to participate in a discussion program on national public radio concerning sexuality and aging men (Jorma Hietaneva, "Miesten tunti: Seksuaalisuus ei ole iästä kiinni," April 27, 2015).

> was necessary for his health. "I run for my life," he used to say. I think I will start using a new slogan: "I write for my life." (Heikki, blog entry "I'm writing for my life," 8/31/2016)

Heikki tended to update his blog very frequently. During the most active years, he blogged several times per day, and after the active phase of cancer was over, he has continued blogging almost daily. In one of our discussions, Heikki explained his need for blogging in the following manner:

> Heikki: It's like with my paintings. I never wanted to paint works that just pile up in the corners of the room. In the same way, I did not want to write just to the drawer.
>
> I: So, for you the communication is the most important?
>
> Heikki: Yes, I feel that I exist via people. If there were no other humans, I would be nothing. Because everything we have has been given to us by others. Without them we would be just shallow bodies. I live when I am in interaction with others. This [blogging] is one way to achieve that. (Heikki/3)

The support that Heikki felt coming from his readers was significant to him. Even though Heikki had supporting family around him, the cheering messages he received from his readers were vital; he said that he felt as if his readers were carrying him through the hard times (Heikki/3). In this way, Heikki's connection with the actual blog writing, as well as with his readers, was rather concrete; his existence was mediated via the internet. This reflects Feenberg's claims about online communities as forms of "virtual embodiment" (Feenberg 2006: 193): instead of being expressions of disembodiment, the online presentations of ourselves are part of us. At least for Heikki, his blog seemed to be a form of his "extended body" (Feenberg 2006). Furthermore, writing itself became a ritual, which helped him to get through the worst moments.

Writing (or narrating in general) has been regarded as therapeutic in itself, yet writing is an activity which easily becomes ritualized (see Kellogg 1999).[188] Autobiographical writing about various chronic—and at times terminal—illnesses has been trending (especially in the USA) since the 1980s (on "autopathographies," see Couser 1997).[189] In the 2000s, much of this kind of autopathographic writing moved online and became blogs (Sofka 2012). Nowadays, medical staff may even recommend patients to write publicly about their experiences of serious illness.

[188] Since Arthur Kleinman's *Illness Narratives* (1988) and Frank's *The Wounded Storyteller* (1995), there has been a movement within the study of medicine, namely, "narrative medicine," which emphasizes the importance of narration by patients and empathic listening by physicians.

[189] As a reason for this, Thomas Couser, an emeritus professor of English (and the founder of the Disability Studies Program at Hofstra University), has speculated that since medical efficacy has increased, diseases and the sense of illness have become anomalies, unnatural states of body/mind; as events in one's life course that are noteworthy, they are narratable (Couser 1997: 9). Couser (1997: 9–11) also notes that simultaneously with the triumph of scientific technological medicine there has been increasing dissatisfaction and distrust among the public toward the medical establishment in the US. In the wake of the patients' rights movement in the US in the 1970s, patients have started to challenge and resist medical authority. Understandably, this tendency has only increased since the internet has made self-diagnosis more possible. Additionally, since medical practices are often seen as alienating and objectifying (Couser 1997: 10), there are now more attempts to reclaim one's own voice.

It is not only the therapeutic and possibly empowering effect that writing can have for the writers themselves, but especially in regard to death and dying some believe that blogging can create a positive societal shift of perception regarding the end of life (see Recuber 2017).[190]

"I write my day"

For Heikki, the ritual of writing kept him anchored in life. For others, such as Inkeri and Marjo-Riitta, writing served as more of an existential inquiry about life and death—a study about living in the liminal space of a terminal illness. The name of Marjo-Riitta's blog was particularly telling: *Syöpä tarinoituu todeksi*, "Cancer narrates itself into reality." Words were not just letters on the screen for Marjo-Riitta; rather, they had the potency to create reality and render things possible. Writing for Marjo-Riitta was exactly the kind of virtuality described by Kapferer, a space in which one can reorient and redirect oneself, and where one can make, or imagine, things to become (more) real.

Marjo-Riitta was a mother of three in her forties; her youngest was only four when she was diagnosed. When I met her, three months before she died, we talked about the meaning of social media to her. Facebook, and especially the closed Facebook page for women with breast cancer, meant a lot, and it was an important source of support. Marjo-Riitta said that she preferred social media over a conventional support group, such as those organized by cancer organizations. She had gone to one once, but that was not her thing: "I just don't get anything out of that kind of rambling conversation over coffee. I need something more substantial and goal oriented" (Marjo-Riitta/1). "On Facebook, you can always pick and choose what to read," she added. Another very significant way to process everything came to Marjo-Riitta in the form of the documentary series *Avec Tastula*, in which she was asked to participate by the nationally well-known journalist Maarit Tastula.[191] In time, the production of the documentary became so therapeutic that she felt she did not need any formal therapy. Long before the documentary, however, already in 2012, Marjo-Riitta had started to write her blog.

Before engaging in writing, Marjo-Riitta had been reading other women's blogs about breast cancer, and she felt that such blogs were useful for analyzing and organizing one's own experience, especially the chaos one was going through (Ressler et al. 2012). In addition to creating a sort of mental coherence about all that is happening when one falls suddenly ill, blogging can also effectively shape one's daily rhythm and time at the moment of serious illness when the usual everyday routines are missing (Stage 2014). Cancer blogs were not only informative, Marjo-Riitta explained, but they made you realize that you were not alone; they created a sense of community (Marjo-Riitta/1) (see also Stavrositu 2014). Furthermore, the manner in which these blogs framed the illness process was an important aspect for Marjo-

[190] While there has been considerable scholarly discussion in the media on the visibility of death, the media does not necessarily cover issues of everyday vulnerability and "ordinary deaths."

[191] In the end, the documentary had two parts. The first part was filmed in 2014 (YLE 1, aired 12/12/2014) when no one knew for sure how Marjo-Riitta's cancer was going to advance, while the second part was filmed in the last weeks of Marjo-Riitta's life and aired only after her death (YLE 1, 4/17/2017).

Riitta. In the beginning, just after the diagnosis, since one was not able to foresee any future, everything seemed so gloomy and scary. In that situation, reading about other people's experiences gave some shape to the future, and she was able to envisage some possible scenarios for herself, Marjo-Riitta explained. The online sphere offered a range of possible worlds, akin to Kapferer's ritual virtuality. According to Marjo-Riitta, this represents a crucial moment in the illness trajectory, in particular the moment when one first receives the diagnosis about a serious illness and is then sent home with sick leave. To be at home alone with a life-threatening diagnosis was not easy, especially since the waiting time for doctor's appointments and various procedures could be weeks. (Marjo-Riitta/1.)

Since Marjo-Riitta loved writing, she decided to start her own blog. Interestingly, she also noted that not just writing was significant, but especially writing *publicly*: "It was an intriguing thought that anybody could read my texts" (Marjo-Riitta/1). Echoing Feenberg's description of the extended body, she was not only practicing her agency via writing but by writing on her terms she also moderated how she might be objectified by others. Marjo-Riitta also recognized that her blog stood out from many, or at least she drew this from comments made by her readers:

> There are sisters[192] who actually come to me in some public events and thank me for the documentary and for the blog. I've been told that they have gotten the most comfort and consolation from my blog, over all other blogs, or anything for that matter. […] They tell that [via reading my blog] they have been able to get ahold of their own emotions and situation, and that they've somehow come to understand what's happening to them.
>
> Also, there is this battle rhetoric that you have to *fight* and be the *most positive person*: "Go, go! Don't give up!" I find that world repugnant, as it starts so literally at that moment when you learn that you have cancer. Everybody comes telling you, "You gotta fight now and stay positive!" For fuck's sake, if you get the flu you are not told by everyone to "keep a positive attitude!" And what it does, what kind of effect this kind of attitude has, is that then one is even less able to encounter these sorts of difficult things and emotions, which one gets terribly a lot after being diagnosed with cancer. As if one should then frantically try to ward off all that is negative, because one should not be somber… (Marjo-Riitta/1)

We continued the discussion and thought together that perhaps this kind of reaction was actually a way to avoid facing the suffering other by totally bypassing the issue with insistent comments such as "keep fighting." To talk and to hear about suffering was not easy, Marjo-Riitta reflected, but in her blog she wanted to be able to express exactly how she felt, describing her experiences honestly, however harrowing they might be.[193]

Marjo-Riitta offered a multifaceted analysis of her own existential situation, and often she examined her lifeworld specifically in relation to words and language. Language and writing formed a space in which she was able to practice her understanding of herself and her situation; thus, writing became the virtual place where she brought together the elements she needed in

[192] Among breast cancer patients, it is customary for women to call each another "sisters."
[193] After beginning her blog, Marjo-Riitta had been invited to contribute to a publication on logotherapy regarding suffering and death. This text ("Elämän sietämätön hauraus," Karhunen 2015) was based on her blog writing, and it also comprised an edited version of her final assignment for her logotherapy studies.

order to work with herself within the painful situation. It was also the space in which Marjo-Riitta was able to take refuge. By writing, she sought to create a space of/for hope and beauty; writing enabled a new and personal relationship with her illness, and perhaps with the coming death:

> I don't care to hear… I'm not able to hear anything more about my blood, my liver, my bones, my lungs, nothing, nothing at all. If I don't hear about them, is everything then fine?
>
> If I write my day to start in such a way that there are no examinations whatsoever at all, will I then be happy for just one single day? Would everything be different if I could be safe even in my dreams, in my sleep?
>
> Sun, my friend, help me to write about beautiful things. I can write myself exactly the kind of day I want. Look, a tree. Look, a bird. Look, a human.[194] (Marjo-Riitta, blog post 3/24/2014)

In her writing, Marjo-Riitta reflected on the relationship of words and thought in relation to her illness:

> The one thing that I am not always able to think of calmly is the existing spread in my spine, that is, the metastasis in my vertebrae. I always refer to it somehow unconcernedly. With a few words. In a subordinate clause. I am not yet able to face this subject properly. And what about my newest companion then, the bone marrow spread. With that, it's beeping even more busily. I am not able to think whole thoughts or write full sentences.
>
> I always wish to change the subject. Spine and bone marrow are fatal places. Especially the spine. Here I come against the limits of my thinking, the wall stands up and I don't have the force to climb over it.
>
> And I don't need to, yet. It is the least I could do now, the climbing. I will surely learn in its time what lies behind that wall.[195] (Marjo-Riitta, blog post 12/30/2014)

In the end, Marjo-Riitta also wrote about the space where words ceased to be:

> I continue writing. In my own way.
> One thing that affects my writing is that the more I spend time on my own, the less I have words.

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[194] "Minä en nyt haluaisi jaksaisi haluaisi kuulla verestäni, maksastani, luistani, keuhkoistani mitään en yhtään mitään. Jos en kuule niistä onko silloin kaikki hyvin? Jos kirjoitan päiväni alkamaan siten ettei mitään tutkimuksia olekaan, saanko olla yhden päivän ainoastaan onnellinen?
Olisiko silloin kaikki toisin jos edes unessani olisin turvassa, elämä olisi turvallinen?
Aurinko, ystäväni, auta minua kirjoittamaan kauniista asioista. Minä voin kirjoittaa itselleni juuri sellaisen päivän kuin haluan:
Katso – puu.
Katso – lintu.
Katso – ihminen."

[195] "Se mihin en aina osaa suhtautua rauhallisesti on tämä minun olemassa oleva selkärangan levinneisyys, siis etäpesäkkeet nikamissa. Viittaan tähän aina jotenkin puolihuolimattomasti. Muutamalla sanalla. Sivulauseessa. En pysty vieläkään kohtaamaan tätä aihetta kunnolla. Entä ihan uusin kumppanini, luuydinlevinneisyys. Sen kanssa vasta tuuttaakin varattua. En pysty ajattelemaan kokonaisia ajatuksia, kirjoittamaan ehjiä lauseita.
Haluan aina vaihtaa puheenaihetta. Selkäranka ja luuydin ovat paikkoina niin kohtalokkaita. Varsinkin selkäranka. Ajattelun rajani tulevat vastaan, nousee seinä pystyyn enkä jaksa kiivetä sen yli.
Eihän minun vielä tarvitsekaan. Koska vähiten kiivetä jaksaisin. Saan sitten aikanaan varmasti tietää mitä kaikkea sen seinän takana on."

The world beyond the words is a beautiful experience.
There is nothing to be afraid of.[196] (Marjo-Riitta, blog post 12/12/2014)

As a ritualized practice during terminal illness, blog writing can be interpreted as a way to create and strengthen connections with people and with the world at large—and ultimately with life itself (Olson 2007).[197] Blog writing is not a diary-like self-expression or monologue, but rather a reciprocal communication, often concretely so, where readers engage in a dialogue with the writer by leaving comments. By writing a blog, one can strengthen the social bonds one has—or wishes to have—with the world. At times, writing for Marjo-Riitta became a corporeal exercise for living. Yet, simultaneously at such moments, as described above, it appeared as a mental exercise for dying. Hence, the ritualizations aiming to avoid death and the ritualizations of preparation for death were not as exclusive as they may sound. Patients may have wished for the former but nonetheless prepared for the latter, at least on some level of their psyche.

9.3 Rituals of preparation for death

Tying up loose ends

British sociologist and death scholar Tony Walter ([1994] 2002) has said that in today's Western secularized world, it is psychological counseling that people wish for themselves in the vicinity of death and dying, not religious rituals.[198] Personalized counseling and different kinds of peer support groups are indeed modern ways to manage crises, but I witnessed people also needing to *do* other things than just talking. No matter from what perspective one looks at it, approaching death is always significant, and merely "sitting and waiting for death" (as someone put it; D4: 31) without doing anything (about it) seems atypical for people.

In regard to contemporary post-mortem rituals, Walter (1996a, 1996b) notes that they tend to revolve around various aspects of the *end of life* instead of the *afterlife*. My ethnographic experience is analogous with this: rituals of preparation for death were mostly about this life and the ending of it rather than death or afterlife. However, because of the finality of death, concrete preparations for leaving this world (such as writing a will or planning details for one's funeral) were often not mere practicalities requiring attention; they easily became ritualized practices for the acceptance of death.

The practical preparations which I witnessed among my research participants fell mostly into the following categories: financial arrangements, sorting of materials and possessions, sharing knowhow and necessary practical information about the household, and funeral planning. At first I did not necessarily think of these as *rituals*, but after spending more time in

[196] "Jatkan kirjoittamista. Omalla tavallani. Yksi asia mikä kirjoittamiseeni vaikuttaa on se, että mitä enemmän olen omassa rauhassani, sen vähemmän minulla on sanoja. Elämä sanojen tuolla puolen on kaunis kokemus. Siinä ei ole mitään pelättävää."
[197] A recent article on blogs about terminally illness demonstrates how blogs were used for construction of a *postself* for the dying blogger. This construction happened through the writing of bloggers themselves but also by the bereaved, who continued their relationships with the deceased via these blogs (Schilderink & Venbrux 2019).
[198] In Finland, psychoanalyst Pirkko Siltala (among others) has written about the importance of psychotherapy for dying patients already from the 1980s on (Siltala 1985).

the field with my research participants, and also with my mother, I came to realize that performing these practices was intertwined with other meanings than just the most obvious ones. These practices were framed by the awareness of death. This awareness constituted another layer of meaning in the practices, which were now also about farewells, either between the dying and their loved ones or between the dying and their life in general (places, memories, pets, etc.). Moreover, these activities often appeared to comprise a kind of a threshold or goal post, a significant point to cross in one's terminal path. Performing these activities created the space in which one could somehow come to terms with the imminent death—or at least come closer to an acceptance of it. Thus, these concrete deeds served as rituals with potential ramifications and innuendos which were not immediately obvious.

Kimmo, among others, had made arrangements involving his finances. Furthermore, he told that he had taught his spouse to take care of the practicalities in their household which had previously been under his domain (D1: 74). In families of two adults, information about insurances, mortgages, and so forth was discussed and new responsibilities were shared. At times, these things were extremely practical, such as teaching about the heating system of the house or how to back up the trailer to get firewood (D3: 13). Eeva and Oiva talked at length about sorting their possessions and getting rid of unnecessary stuff. This was especially a concern for Eeva, as she did not want to leave it to her child to sort out her belongings (D1: 76–79). Aili had designed her whole funeral program, including the text for her obituary and the hymns she wished to be sung during the service (D2: 31). Shifting thinking away from one's next treatment or a new drug trial to funeral planning marked a significant change in the final days.

Sometimes the change was expressed in more mundane terms, albeit not less significantly. Oiva was an artist in his seventies with a rich life history, and he continued to express a Spinozian sense of joy and curiosity about life, even during his very last weeks and days. As mentioned above, the embodied experience of dying was somehow a surprising experience to Oiva. Even though he had been suffering from cancer and other illnesses for a long time, he was still intensely connected with life, and his deteriorating body seemed to truly astonish him. A couple weeks before his death, he told me that he had passed a sleepless night because he had been doing some thinking. The day before, he had noticed in the newspaper an obituary for an artist colleague. This prompted him to give up his fast sports car and pass it on to his son. To formalize this decision, he had sent an email to that effect. Based on our conversations over the eight months I had known Oiva, I knew that he loved that car a great deal, and even though he had not been able to drive it for a long time he had still not surrendered it. Now he finally did. I saw this gesture as a meaningful symbolic act: giving the car away was for him a clear sign of resignation from life, something that he was willing to do only at the very end. (D1: 115.)

At times, the preparation seemed to involve ritualized grieving over a previously deceased loved one or a fellow patient at the hospice home. Sometimes my research participants in the day hospice started spontaneously talking about the funerals of their beloved. For me these moments signaled that the person had started to shift in their orientation. Witnessing the passing of fellow patients served as a sort of preparatory practice, as seen with the memorial candle in the day hospice room. Although Eeva had already prepared for her death in numerous ways (e.g., sorting her things, making her death shirt), she "rehearsed" through the passing of her fellow patients. She spent several weeks on the hospice ward before her death, and so she had had time to create some close connections with a couple of patients; even at the end of her life, she formed short yet meaningful friendships. With one, she had agreed that they would attend each other's memorial services, whoever would die first. (D1: 104–105.) When the friend died before Eeva, she felt sad at the loss. On the day of the funeral, when I phoned her, she tried to be stoic: "I am trying to be like on any other day. This [death] is part of this house, isn't it?" (D1: 123). Attending the service was important to Eeva, and she was happy to have a beautiful white rose to put on her friend's coffin. The simple ceremony was held at the hospice home, and it included only the blessing of the body. Since she did not witness the actual burying of the coffin (I presume that the coffin was sent to the crematorium), Eeva felt that the ceremony had been incomplete (D1: 124–125). This, in turn, prompted Eeva to plan her own funeral in more detail. A few days later, she told me that she had completed a set of papers concerning the logistics for her own funeral. (D1: 126.)

A visit to the funeral home

My mother did not talk about her future or the approaching death, and it was actually difficult to talk about the situation with her at all. This suddenly changed about a week before she died. We were in a car shop buying new winter tires, waiting in the lounge while the mechanic was putting them on. Unexpectedly, my mother asked me if I knew if it was possible to be buried without a coffin. I was surprised about her choice of conversation topic, since I had been hoping to talk about these sorts of things but until then it had seemed impossible. I answered that I was not sure but we could find out.[199] From there, the conversation went into various details of her funeral, such as the newspaper obituary, in regard to which she had a specific wish. After we left, I drove us downtown by the river. Walking was getting harder for her, but since it was a very beautiful and sunny day and the autumn trees were at the height of their beauty, we thought of making a little walk. We parked the car, and by chance I noticed a funeral home just around the corner. I pointed it out to my mother, and together we decided to drop in.

[199] There is no legal obstacle to burying a body without a coffin in Finland, but since it is difficult to move a body without one, it follows that burials without coffin are very rare (https://www.finlex.fi/fi/laki/ajantasa/2003/20030457). The coffin does not need to be made of wood, though. In order to hasten decomposition, cardboard and like materials are also used. However, since in practice the coffin needs to be strong for transportation, most people still use a conventional wood one. Furthermore, crematoriums require bodies to be in a coffin (http://www.krematorio.fi/fi/tuhkaus/tietoa-tuhkauksesta; personal communication with an officer of The Finnish Cremation Foundation, 11/22/2017).

As we entered the funeral home, a neat-looking man in a suit came to serve us. “We came to choose a coffin for me,” my mother told him bluntly. Without blinking, the funeral director guided us to sit down on comfortable chairs around a small, round table. He served us coffee, juice, and cookies, and then brought all the binders from which my mother could choose a coffin and death clothes to her liking. The funeral director answered her questions in a restrained, quiet manner, and helped my mother to make her choices. After deciding on the coffin and the clothing, we went to look at the different kinds of urns on the shelves. My mother chose a decomposable clay urn with a painted picture of a boat sailing toward the horizon. The funeral director wrote down all the details on a sheet of paper. Everything was done respectfully and in a quiet, yet matter-of-fact manner which shielded my mother—I thought—from possible painful emotions underneath this important moment. At one point, my mother asked the funeral director if it was unusual to have the *actual* client themselves ordering their coffin and so forth. Rather expressionlessly the funeral director told us that actually it was not, and every now and then they had people buying their own funeral arrangements. The whole experience was significant for both of us. Until that moment, there had been no discussion of any of the details relating to her imminent death—and now we were at the heart of the matter.

When we left the funeral home, I felt that things had changed. We had somehow officially acknowledged that she was dying. *She* had acknowledged that she was dying. I felt that our visit to the funeral home—however unplanned it had been—was a ritualized preparation for her dying. The formal and subdued personal service by the funeral director made the moment unlike any ordinary shopping experience. This moment embodied Kapferer’s interpretation of ritual as a kind of virtuality in which ritual participants can invite change for themselves or practice new solutions and transformation. The space at the funeral home enabled the thought of death to be approached and exercised. The possibility of becoming a corpse was invited into actuality via the virtual ritual practice.

Death cleaning as a practice of agency

I learned one powerful example of preparation for death with Kirsi when she invited me to her home one late summer afternoon. As mentioned in the prologue, Kirsi had been diagnosed with lung cancer already years before. She had gone through a pneumonectomy (lung removal), and ever since she had been on disease-modifying medication. Because of her severe prognosis, she had been referred to the hospice earlier, and she had been attending the day hospice group already for a long time. Sitting at her kitchen table, we had a lengthy interview and conversation concerning her extensive illness trajectory and its effects on her life. Being severely ill for so long had changed Kirsi’s social life completely, and now she suffered from rather severe loneliness. She talked about the loneliness openly, but it was also tangible; she seemed to have an immense need to talk and share. As a solution for her loneliness, she had found writing. She attended a therapeutic writing course, which turned out to be a critical method of self-healing for her. (Kirsi/1; D4: 29.)

What impressed me the most about Kirsi was actually her home. After our conversation, she showed me around her three-room apartment. While we were sitting in the kitchen I had not noticed anything unusual, but as soon as we entered the living room I realized that her house was nearly empty. The apartment almost looked like it had been robbed, or that she was in the middle of moving; most of her things, including the furniture, had already been taken. The living room was practically empty. When I made a comment about this, Kirsi just laughed. She had started her "death cleaning," she said. In practice, this meant sorting her stuff and giving her property away.[200] Kirsi appeared to be still in quite good condition, so I was a little surprised about her determination in regard to the "preparation," which essentially had to do with sparing her only child the need to deal with all of her stuff after her death. In the end, Kirsi lived for well over a year after our meeting. (D4: 29.)

While Kirsi's example was extreme, it was not unusual for patients to perform some sort of cleaning after their diagnosis. For instance, Eeva talked about organizing her stuff a number of times during the few months I knew her (D1: 76–78, 88, 138). She told me that right after she learned about her diagnosis, she started a big cleaning and organizing (*suursiivous*) of her home: "I started to throw stuff away, to empty the closets, and to take some clothes to recycling. I had quite the whim to do it" (D1: 76). As stated earlier, it seemed to be easier to do something rather than just merely sit on the news.

Eeva told me that she had already burned her diaries years before, and now she was going through all the other stuff. "I am content that I have been able to get rid of all the stuff that does not mean anything to anybody else," she noted practically. I asked her, "But those things have mattered to you?" She answered, "They meant something a long time ago. But it is so long ago, those emotional ties are now long gone." At this point, there was just a sense of relief in letting go of everything. (D1: 77–78.) A little later in our conversation, Eeva started wondering if she was somehow cold-hearted, since she did not have any sentimental feelings about getting rid of her things. Even her brother had commented to her that she did not need to act so cool, to which Eeva had simply stated that she was not acting: "I just know what is going to happen here" (D1: 88). As noted earlier, Eeva's approach to her death was practical and calm. And while she mentioned a similar motive to do her death cleaning as Kirsi—namely, that she did not want her only child to have to go through all her stuff—it occurred to me that it was also maybe a matter of privacy. The way in which Eeva told me that she wanted to "tear into pieces some old papers" made me think that this was perhaps a way for her to practice agency; the material stuff mediated her subjectivity, and perhaps there were parts of herself that she did not wish to reveal

[200] Since the Swedish 83-year-old artist Margareta Magnusson published her book *Döstädning: Ingen sorglig historia* (2017), released in English as *The Gentle Art of Swedish Death Cleaning* (2018), the concept of "Swedish Death Cleaning" has become known around the world. A few years before Magnusson's book, the much-loved Finnish poet Eeva Kilpi published her poem collection called *Kuolinsiivous* ("Death Cleaning," 2012). I do not think it a coincidence that both of these authors addressing the issue are women (even though for Eeva Kilpi the "death cleaning" functions more metaphorically). Both of them write, albeit in a very different manner, about living while remembering death's presence. It is noteworthy that among my research participants, only women spoke about cleaning and organizing the house as something to do before death.

to others (D1: 88). Taking care of one's own death cleaning can be seen as an act of authority over one's mediated being—as well as one's dying subjectivity. Furthermore, *tearing* and *burning* are not just simple gestures of "throwing things away"; they can be seen as signifying a more symbolic manner of letting go. When something gets disposed of, there is more room for other things.

Even though I do not want to read any more meanings into the death cleaning than what there might actually be, a scholar of religion should note the age-old connection between cleaning and religious purification (Douglas [1966] 2002). From this angle, death cleaning concretely resembles a spiritual cleansing, purifying gesture. Furthermore, cleaning is meaningful on different levels: hygienically, organizationally, symbolically, and spiritually. As anthropologists have shown, rituals and ritualizations around death and dying are multiple and culturally rich and varied (Metcalf & Huntington 1991; Davies 2017), yet at times they may share surprising similarities. The practicies described here illuminate the less studied perspective of the preparatory rituals of dying, thereby bringing into view some contemporary individualized and secularized variations of death rituals.

10. PARTICIPATION, AESTHETICS, AND METAPHYSICAL IMAGINATION

10.1 Religion as participatory experience

Religious and spiritual orientations

In the course of my ethnography, I encountered a few patients for whom religion or a spiritual orientation to life was particularly strong, and they drew from spiritual sources throughout their lives. For most of my research patients, however, their religious views were somewhat fluid, and religion or spirituality did not seem to significantly affect their everyday life, not even prior to death. If the theme of religion did not come up on its own, I usually asked about it at some point in my relationship with the interviewees.

In regard to religion, Aili often reiterated that she respected the Church (meaning the Finnish Evangelical Lutheran Church) for what she considered it had done for the sake of Finland, but she did not really care for its actual religious teaching (Aili/2; D1: 19). Aili's attitude toward the Church represents the majority view in Finland: the societal work that parishes do in Finland is well appreciated among most of the Finns (Ketola et al. 2016: 219). In regard to faith, according to Gallup Ecclesiastica, a survey study concerning the religious beliefs of Finns published every five years, 52% of the population "believe in God," but only 33% "as taught in Christianity" (Ketola et al. 2018: 43). Even though Aili did not consider herself a believer, there seemed to be something reassuring in the Christian customs: "It is clear that for me, the religion is not… it isn't any rescue… but when things go really badly, then one can fold the hands into a prayer at night" (Aili/2). Aili referred to the "folding of the hands" several times during our conversations, usually when she was contrasting her way of believing with that of the Church: "My faith is different. I fold my hands and then there is some kind of a connection" (D1: 19). I took this to mean that there was something consoling in the embodied praying gesture, which she had learned from her mother (Aili/2). It was as if the religious mode (her very own mode) was activated or turned on by this ritualized gesture, although conceptually Aili was not interested in religion.[201] On the other hand, she never referred to an actual moment when she would have made a prayer. The ritual gesture of prayer can be interpreted as a creation of the kind of ritual space in which consolation and reorientation were made possible.

Aili did have some experiences of supernatural things, however. One day in the day hospice group we started talking about the old Finnish spiritual traditions of the "bird of the dead" (*kalmalintu*) and the "soul bird" (*sielulintu*).[202] Actually, many group members had experienced something unusual and special, perhaps supernatural, in regard to birds and death. Aili told that even though she did not usually believe in "these kinds of things," she had had an experience

[201] On embodied religious activities among older Orthodox women in Finland, see Kupari 2016.

[202] The *kalmalintu* refers to a bird that foretells approaching death, whereas the *sielulintu* can be seen as a manifestation of the soul of the deceased, which visits grieving family members (Pentikäinen 1990: 63; Holmberg 1915: 14; see also Butters 2017). Both of these are part of pre-Christian religiosity in Finland. Furthermore, the imagined connection between death or dead with birds seems universal; there is evidence of death-related folklore about birds worldwide (Moreman 2014).

with a small wagtail just after her husband died. This little bird came to her for three or four days in a row when she was in her community garden plot. The bird just stayed around, hanging out there with her in the garden—as if it was coming to greet her from the otherworld; indeed, the "soul bird" (*sielulintu*) is traditionally understood as a manifestation of the soul of the deceased (Honko et al. 1993: 610). This experience had deeply impressed Aili, since she talked about it to others and me every now and then (D1: 2; D2: 116–117). She said that she had never believed in "anything like that," but after this bird had come to her she started thinking that "something must be out there" (D1: 2). As we shall see, nature in various aspects was the main source of solace for Aili, and it was the place where she believed she would end up after her death. Furthermore, as we shall see, birds also came up in other stories as especially meaningful creatures relating to death.

If Aili respected the Church, Peter told me flat out that he despised it. He did not believe in God, yet he admitted that it was possible that there was "something more out there" (D1: 59). He told me that he was interested in Judaism. Kimmo, in his turn, told me that he had had a Christian upbringing, which had left him with Christian values (D1: 119–120). He felt that his faith was "somewhere in the background of everything," guiding him especially in regard to ethics. He had never had any supernatural experiences, he said, but continued pensively that "having one could have been exciting" (D1: 120). Eeva belonged to the Orthodox Church but she defined herself as "hardly spiritual." When we discussed this, she reminded me that in the "old days," when she was a child, being Orthodox was something not to talk about. This had to do with Finnish history and World War II with the Russians (which caused numerous Finns to change their faith from Orthodox to Lutheran Christianity). More recently, she told me, she had taken a couple of her friends to the Uspenski Cathedral in Helsinki, and she realized that now she was able to feel proud of her beautiful church and the splendid singing there (D1: 93). As for her actual religious faith, however, Eeva was not quite sure. The priest had visited her a few times when she was on the hospice ward, but, according to Eeva, they just talked about this and that, nothing personal nor spiritual. She admitted that she thought about spiritual things quite a bit, but nothing was certain. In the end, she summarized her religiosity by saying, "I am just like the others. I believe a little bit—but not really, however" (D1: 93).

For most, their religious denomination (or lack of one) did not seem to affect their everyday life, not even in the face of death—although for some (as we shall see), their spiritual views probably affected their general approach to life as well as death. When I first met Oiva, he told me right away that he believed in God: "Not the way in which the Church teaches," he clarified, but "it is clear that God is everywhere." Oiva described himself as "a pantheist" (this was his exact own wording): "I should not maybe say this out loud but it feels like a good idea to me that God is part of everything" (D1: 12). For Oiva, God seemed almost more like a natural fact than a matter of religious belief. He also told me that he had had two near-death experiences earlier in his life; he had even seen a tunnel of light, which had been inviting to him. Due to

these experiences, Oiva said that he did not fear death; he knew there was a place, or "perhaps not a *place*—that sounds too limited—rather a *state* or *mode* of being, which is close to nirvana, or something" (D1: 12). About a month before Oiva died, when his condition had deteriorated quite a bit, he reiterated that he had no fear. He said that he knew that no medications would help him anymore: "There is even a certain sense of destiny here. I feel myself like some sort of Native American, to rise up to that high mountain and then dive down from there, and that would be the end of it. I am not scared. I am not scared at all" (Oiva/1).

Supernatural experiences and the question of afterlife

Similar to Aili, Taina also had had some experiences about the felt presence of a dead relative. The first time happened the night her husband was dying at the hospice home. Her husband had appeared to her grandchildren, who were around ten years old at the time:

> It was interesting, the children had gone to sleep at home, and when their mother returned home [from the hospice] early in the morning and was about to tell them that "your grandfather has…" They interrupted her and said "Yes, we know" He came and told us already!" Can you believe that!? Guess who got goose pumps about this! (Taina/1)

Taina continued by reiterating how amazed the whole family had been about this, but then she added that actually she had had her very own experience about her husband's presence after his death:

> One evening before going to sleep, I was standing by his picture and I was looking at him and thinking by myself about everything that we could have experienced together had he not died… I was fully awake and everything, when suddenly I heard his voice in my head saying. "Milla [the granddaughter] is not doing well." And I thought to myself that how come she isn't well, I had just seen her that day. The following morning my daughter called me and told that Milla had a 40˚C fever! But I already knew that she was ill. These kind of things… You can think I'm nuts but I have no explanation for these things! (Taina/1.)

Since Taina had had these "hints" of the afterlife or otherworld, I asked her if they had affected her understanding of the afterlife. She said that they probably had, "Even though I would not admit or confess it!" Taina elaborated that she had accepted that "this is it," but she was open to the possibility that there was something more: "I have told my children that [after my death] I will come and talk to them whenever I have something I need to tell. But I've said to them also that if I have nothing to say then I won't come!" Taina laughed and added, "Just in case!"[203] In regard to religion, Taina explained to me that sometimes she did do some "chatting" with God and asked for forgiveness, but she never went to church and did not find their services very important to her. (Taina/1.)

Taina's views, both on religion and the afterlife, were rather typical among my research participants. I did not always ask about the afterlife (especially in those cases in which the

[203] According to Ketola et al. (2018), 33% of Finns believe that it is possible to feel a connection with the dead. Such experiences have been studied by scholar of religion Markku Siltala, whose dissertation on "post-death contacts" (PDC) was defended at the University of Helsinki in 2019.

patient did not think of themselves as dying and the whole issue of death was not discussed). When the topic arose, it often appeared as something which one did not necessarily believe in, yet often the person added that "perhaps there is something more." Kimmo, who believed in God, said that one cannot know anything yet one can hope: "I hope that what I've learned at home would come true, that I would meet some diseased relatives and be with them" (D1: 119).[204] According to Gallup Ecclesiastica, the majority of Finns (71%) agree with the statement that "nobody knows what happens after death" (Ketola et al. 2018: 47). This was also the most common sentiment among my research participants. As Oiva explained to me, there was no point in speculating on metaphysical questions since there were no answers to those anyhow (Oiva/2). The only thing one can do, he added, was to have *trust*; one should not worry about mundane details but rather realize what kind of mystery the human is. This kind of trust was extremely relieving, Oiva assured me, just a week before he died. (Oiva/2.)

According to Gallup Ecclesiastica, almost half of all Finns (49%) believe that "there is something after death but I don't know what" whereas 39% agree that "death is the end" (Ketola et al. 2018: 47). Even though its survey suggests that many Finns believe that death is the end, I did not commonly hear my research participants sharing that view. In terms of thinking of total finitude, perhaps "the end" as some sort of non-existence became challenging in the proximity of death. It was more typical for me to hear vague views, such as "perhaps there is something out there" or "we can never know what happens after death." For Matti, death was "the deep sleep" (Matti/1). Aili and Heidi believed that one will return to the "greater cycle of nature and the universe" (Aili/2, Heidi/2). This idea can be interpreted in multiple ways, emphasizing the ever-continuing cycles of life and the existence of some sort of eternity, or it can be seen as emphasizing the end of one's personal life (or possibly both). This view mirrors the 27% of people who in a Gallup poll agreed with the statement that after death "we blend back into the universe" (Ketola et al. 2018). In sum, a range of views came up in the discussions with the research participants. Just like with Taina, at times one could have several, even mutually contradictory ideas about the afterlife and a possible otherworld. Furthermore, the fluctuating nature of the views was evident. For instance, Taina commented to me that "*for the time being*" she was content with the idea of the non-existence of an afterlife, implying that at some point there might come a moment when she would need to rethink her ideas.

Religion as participation

Religion and spirituality represent a good example of the participatory manner of orienting to reality, which can be seen as contrasting with scientifically oriented medical causality (see Chapter 2). In practice, it seemed that most patients' religious views were so fluid and flexible that they never caused any serious dissonance in their daily lives. Sometimes, however, their views contested quotidian reality. One patient for whom religion played a crucial role was Siru,

[204] Kimmo's perspective does not reflect the teachings of Christianity about the afterlife, yet it seems rather common.

a member of a charismatic Christian congregation whom I met in the day hospice. Siru regularly attended various kinds of spiritual services and healing sessions where miracles reportedly happened (D1: 95). Siru seemed to be constantly negotiating both a causal and a participatory orientation to reality; her trust in her doctors changed from steadfast to suspicious, depending on the practitioner and the phase of her illness, yet her trust in God was absolute until the very end (D1: 95–96; D2: 18, 121). Even when cancer spread everywhere in her body, including her brain, she believed in the possibility of a miracle—that she would not die from the cancer. It was as if she simultaneously lived in two parallel universes; she faithfully followed various—at times very heavy—medical treatments and cancer therapies, and at the same time she participated in evangelical healing sessions, having equal belief in their efficacy. While attending a healing led by a well-known North American preacher visiting Helsinki, she experienced "sensations of warmth" in her lungs (where she had metastasis). To Siru, this was a sign of a miracle. According to her, the next time she was checked the tumor had indeed shrunk from 4 cm to 1.8 cm (D1: 95).

In addition to miraculous healing experiences, Siru experienced her spiritual practice as deeply affective. In our conversations, she described how she was filled with "light, peace, and a soft sensation" while she was praying (Siru/3), and she had strong dreams and visions. One of these happened during a service in church:

> I had my hands in front of me like this (hands together, forming a cup), and the Lord placed a *silver bird* into my hands. It had wings like this and there was a hole in the middle of the bird. I asked the Lord, "Why there is a hole?" He put a white candle into the hole and He lit it and He said, "Let it burn as long as you feel like it." I let it burn and then I blew it out, and I placed it into my heart. What a wonderful peace! These are *real* revelations, you know. (Siru/3)

The kinds of visions that Siru had were aesthetically very pleasing, and they seemed to comfort her greatly. Siru was not shy to share her experiences in the day hospice group. I never heard anyone making any deprecating comments about her convictions; on the contrary, some (as Vivian noted) perhaps hoped that they could have similar faith themselves. Occasionally, though, Siru's visionary personality caused some baffling moments. One Tuesday before Christmas, during a small concert in the day hospice room where one of the volunteers was performing a few Christmas songs, Siru—who was sitting right in front of the singer, facing her—suddenly closed her eyes and placed her hands on her knees, palms up, as if in a gesture of receiving blessings. After the songs were over, Siru announced that she had had a vision: the singer had had two white pigeons on her shoulders, and behind her there stood a big, white angel. The singer had radiated divine light. After sharing her vision with everyone, Siru went and hugged the singer, who looked a little perplexed yet glad. Someone in the group laughed mildly, whereas others only smiled. Siru herself seemed empowered for the rest of the day. (D2: 83.)

A few weeks after Siru's vision, the Tuesday group received two new members, and there was a new spark in the conversation of the group. Patients were talking about the moment when they heard about their diagnoses and the importance of the consulting doctor at that moment, and then the conversation shifted to the acceptance of the prognosis. One person speculated that perhaps she had not quite fully accepted yet that she would die (D2: 92–93), whereupon another said that there seems to be various phases in the acceptance process. The conversation went on until at some point Siru stated, "I don't believe that I will die." For most of us, this was not an unusual comment from her, since she had often told us that she believed in a healing miracle. The new member of the group, however, a woman in her early fifties, commented, "Well, that must be one way to go about it… And surely one's own attitude affects the situation…" After a little pause, she continued hesitantly, "Or do you mean that you *really* don't believe that you will die?" "That's what I mean. I won't die," Siru answered, without any hesitation in her voice, "I will not give up" (D2: 93). These moments disclosed the dissonance that existed between her religious conviction and the general scientific world-ordering shared by most of the members in the day hospice group.

Another example of such a disjuncture happened with my mother and her sudden visits to the healer, whose epistemological lens was strongly magical. I was personally surprised to see how quickly one could move from a scientific worldview to a magical frame. At times of severe existential crises like imminent death, the social pressure to follow the causal scientific orientation becomes practically meaningless. In Siru's case, the explanation of the world shared in her evangelical circle already differed from the dominant narrative of instrumental causality. When there was a strong sense of hopelessness without any source of succor, even those whom I did not find to be drawn to magical modes of thinking could find them reasonable and potentially functional. Of course, not everyone was able to find solace from such alternatives.

Religion as failed participation

Vivian felt let down by religion. Since she had told me earlier that she belonged to the Evangelical Lutheran Church, I asked what Christianity meant for her. "It would be just wonderful if I could get some consolation there," she answered and started sobbing, "But I can't." She mentioned Siru from the Tuesday crew: "She is so strong in her belief. I long for some alleviation from the anxiety that I have, and I am open to anything" (Vivian/2).

Vivian said that she had always been very rational in regard to possible life crises. In her work, she had been accustomed to solving challenging situations by using various kinds of project tools, such as SWOT analysis (focusing on strengths, weaknesses, opportunities, and threats); she told me that she had actually used these in her personal life, in order to find solutions and ways to get through difficult times. Now, faced with her end of life—"the worse-case scenario," she called it—she found these tools useless (Vivian/2). During the earlier phases of her illness, nature walks helped her: "When I get to see some beautiful nature, or a park or flowers, something like that, then momentarily I can free myself from the illness" (Vivian/2).

When I asked Vivian what exactly she was able to free herself from, her answer was the constant sense of anxiety: "I would not think of the illness but observe nature, and somehow take it in me. At home, I am with my thoughts but while I am out in nature I pay attention to that environment around me" (Vivian/2). Outdoor nature quite literally gave her space outside of herself; for a moment, her existence was mediated more via the surrounding environment than via her wasting body. Aesthetics provided momentary relief from the anxiety and fear that burdened her so heavily (Vivian/1; Vivian/2; Vivian/3). When we had this discussion about nature for the first time, Vivian continued to analyze her situation by telling me how she had tried different methods to ease her anxiety, but seeing a psychologist or taking antidepressants did not really work for her. It was the combination of sports—"endorphins," as Vivian put it—and nature that helped her the best. After becoming ill and needing to forget about "sweaty sports," only nature was left.

Vivian continued to seek solace from religion, and she talked regularly with the hospice priest. She told me about a book that the priest had given her to read:

> I am still in the middle of it but I am having some problems with it. He [the author] says that all the troubles will bring something good… And that God has given us all these troubles, which are planned for us with love… I have a hard time accepting his way of thinking. I feel that is… (Vivian/1)

At this point, Vivian started to cry and I turned off my recorder. It seemed like this particular text only gave her more grief, instead of comfort. As the illness progressed, Vivian became increasingly fearful. In one of our conversations, about a month prior to her death, Vivian burst out:

> I am just *so* full of fear! That is the thing. When I've got so much time to think, I have so many different emotions, negative emotions… disappointment… frustration… But at this moment, it is the *fear*. How dreadful this end will be. That is on the surface now, since my condition has worsened… It is the most prevalent of all of the emotions. (Vivian/2)

Vivian was in need of distraction from her fear, yet at this point she no longer able to go outside, and the other possible sources of solace failed her. The last time I saw Vivian was only two days before she died (D4: 27–29). I went to see her at the hospice home, where she was now staying with her mother. Vivian knew that she was dying soon. Her body was swollen and the tumor in her upper torso made her breathing laborious, yet she was lucid and fully conscious. At this point, the more abstract feelings of dread had dissipated, and the only thing she feared was suffocation. She was at ease, however, since the nurses had reassured her about the option of sedation if it came to that. It seemed to me that in the end, her fears subsided before sensations of awe in regard to her physical dying body. She commented on this to me by describing how odd it felt that her legs had "stopped obeying" her and that she could not even recognize her face in the mirror, since everything just looked so swollen and she had lost her features.

At this point, she was declining all visitors, and I felt privileged to be with her. I thanked her for participating in my research, and I said that I believed it took some courage to share all those

difficult emotions she had experienced. Vivian was surprised to think of herself as courageous: "I have never imagined that there could be anyone as fearful as me, I am so fearful!" she confessed. In the end, she died peacefully, without any need of sedation.

Everyone had different tools at their disposal to work with their existential situation. Reflecting the results of Gallup Ecclesiastica in regard to the variety of Finns' attitudes toward religion and death, religion or some form of spirituality brought comfort and consolation to some of my research participants, whereas others could not find solace from religion even after trying quite hard. For many, religion did not really play any major role. Participatory tendencies, however, manifest in many ways and find various kinds of representations—not only religious ones. Furthermore, not all participatory orientations are in dissonance with the hegemonic cultural ideology of instrumental causality. As Hanegraaff (2003: 377) observes, one of the least contradictory ways of being in participatory relationship with the world is that offered by the arts. I would argue that nature offers another one.

10.2 Nature as participatory experience

Nature as therapeutic landscape

Nature[205] seemed to feed participatory experiences of various sorts. For Vivian, aesthetic experiences in nature offered therapeutic breaks from her illness and anxiety, but some of my research participants also found aesthetics to be philosophically, metaphysically, and even spiritually inspiring. Nature features aesthetic elements of rhythm and movement but also quiet and stillness, which serve as allegories for time, and which resonate in various ways with hope, grief, and anxiety. In my research material, the stillness and silence associated with nature were considered restoring and healing. This was evident in the manner in which people talked about their nature trips, summerhouses, or significant moments experienced in natural surroundings. For instance, Kimmo told me that after his diagnosis he discovered nature in a completely new way, different than he had known it growing up as a rural farmer's son. Nature had then been a source of income—it had instrumental value—but now it was a source of awe. Kimmo described to me how he would sit outside in his yard after a sauna and just watch the birds in the summer evening. A quiet moment spent in admiration of nature was a new experience for him, he said (D1: 82).[206]

The healing and restorative effect of nature has been an avid topic of research in various disciplines during the last decades (Nilsson et al. 2011; Kaipainen & Rosenquist 2013; Tyrväinen et al. 2014; Tyrväinen et al. 2019). Since the 1990s, new studies have arisen around the notion of "therapeutic landscapes" (originally coined by Wilbert Gesler in 1992), in which

[205] Here the concept of nature (*luonto*) is used as it came out in the participants' speech.

[206] In a Finnish study on the connection between nature and silence, the latter has been explained in terms of small sounds and voices. In other words, silence is never absolute; rather, it makes it possible to "hear better" (Ampuja 2014: 263). This articulation of silence also permits spiritual or existential interpretations. In stillness, one may listen to oneself or hear God better (Gothóni & Gothóni 2014).

the physical and mental health effects of different landscapes and environments are taken under analysis (Gesler 2009; 2005). The following account told to me by Helena exemplifies the notion of the therapeutic landscape.

Helena's previous apartment had had huge windows opening onto a forest: "There was nothing else to see but nature, nothing but trees. I took all the curtains away so that there would be nothing obscuring the view. It was an insanely enchanting view at any time of the year" (Helena/1). She told me that during the worst bouts of pain and discomfort, when she could do nothing but lay on the bed, she stared out of the window for hours: "I felt like there was always something to see, in the clouds or in the trees and leaves. It was really the *salvation of salvations* for me" (Helena/1). Much like Vivian, Helena explained that perceptually immersing herself in nature offered moments that were free from pain and anxiety. Helena considered her ability to "plunge" into the landscape in this way as a special "skill" (Helena/1).

The discussion on the healing effects of nature goes back to the so-called biophilia hypothesis, which can be described as "the passionate love of life and of all that is alive" (Fromm 1973). Biologist Edward O. Wilson (1984) proposed that the human tendency to focus on and affiliate with nature and other life forms has, in part, a genetic basis, whereas the *Encyclopedia Britannica* defines 'biophilia' as the "idea that humans possess an innate tendency to *seek connections with nature* and other forms of life" (Rogers 2018, italics mine). The word 'connections' is the key here. I find that many of the special moments referred to in my ethnography are about *seeking connection*, whether it is with nature, other sentient beings, or supernatural agents or forces. In regard to aesthetics, I propose that the experienced enchantment of nature (or *with* nature) has to do with the smooth and chaotic but lively movement that is present everywhere in the natural world. By providing a contrast to striated order and predictability, nature reveals random, unpredicted spaces for hope.

Participatory experiences with nature

Aili spoke about nature with enthusiasm. In her speech, she often linked nature to her identity as a Karelian evacuee and a daughter of a farmer, who grew up in the countryside. Aili construed nature and her relationship to it in a different manner from Helena; for Aili it was not so much about beautiful sceneries or therapeutic landscapes but about *physical involvement* with nature, especially with soil.

The idea of biophilia describes Aili's relationship with nature quite well, since for her the significance of nature was expressed in references to the embodied experience of connectedness and intertwined relationality. For more than thirty years before her diagnosis, Aili had cultivated a small plot in a local community garden. This plot had become even more important after her husband's death and the need to give up their summerhouse, an old farm in the countryside. In our conversation at the hospice home, Aili analyzed her relationship with nature by saying that nature for her was foremost about land—farming it and growing food in it. This was her blood heritage, she said:

> Somehow, the soil and the field… That's where it all comes from. Farming and nature are such important things. One grows into it. For my father, rye bread was so important, and it had to come from one's own land. He was a farmer. The best picture [I have]… He had a beautiful pair of horses, so wonderful… and when I reflect on it, that thirty hectares every autumn with that pair of horses and a single plow… when I come to think of it, it was like doing a service to God. Although there was no longer one's own land, which remained [on the other side of the border] and he never stopped missing it, there was, however, a plot of Finnish independent field. It was so important in my family—did I tell you about this? When I asked my mom what she thought after the Winter War, [she said], "at least, we were left with a piece of this land… and this land is terribly important, important to father." And the grain… There he wanders around [in the fields] with a sheaf of grain in his hand… (Aili's voice cracks) Nature is important. There is no way around it. (Aili/1)

In Aili's narration, nature was inseparably bound with Finnishness and independence, and her memories of the lost home in Karelia were a part of that. Nature as land was about livelihood and family, generations and history; it was not only about Aili's personal connection with farming and gardening but also the connection with past and future generations.[207] Aili noted that her and her husband's relationships with nature were different, since for him nature was primarily about forests, trees, and birds, whereas for her it was about "the field and crop and all that where the bread comes from" (Aili/1). One spring I visited Aili at her home (D4: 15), and once again we ended up talking about farming and gardening. Aili told me that the whole idea of community gardening, which had given her so much pleasure, had actually started with a suggestion by her child. In the first years, it was something that she did together with her child, and later on she had her grandchildren with her:

> They were sleeping in their prams under the cotton cloth, I had coffee in a thermos and a book with me, and when I got tired I would sit in a rattan chair and read. It was a kind of a community; everybody came there. It was like a way of life. The granny with the neighboring plot even came there with her walker until she died. (D4: 16)

As Aili had told me how important springtime and the new growth in nature was to her, I asked what spring looked like to her now. Aili's answer was blunt: "It doesn't look like anything. It does not *feel* anything" (D4: 17). When I tried to dig a bit more into what she meant by this, she interrupted me and huffed:

> It [nature] does not matter. It does not have a meaning any longer! I do *see* all that. I have seen those liverworts there, and that blooming bird cherry over there on the other side [of the yard], but it does not *mean* anything any longer, because I am not *inside of it* anymore (*mä en ole enää sen sisällä*). (D4: 17)

This was an unusual expression in Finnish: "inside of it." One might ask, how can you be "inside of nature"? When Aili said this, however, it made sense. For Aili, looking outside her window and seeing nature only seemed to cause pain, as it reminded of her personal loss. Since

[207] Similar descriptions of the importance of nature for Finnish farmers can be found in the anthology *Kirjoituksia maan sydämeltä* (Nirkko et al. 2004), which is based on material received in a writing competition organized by the Finnish Literary Society and targeted at Finnish farmers (past and present) in regard to their relationship with land and nature.

she was not able to feel *part* of nature or participate, since she could not actively do anything to create *in* it and *with* it, she inevitably felt like an outsider. When I asked her about this, she said that that was exactly how she felt, "like an outsider" (D4: 17). The same discussion was reiterated at other times when Aili referred to the outside by saying that "it is green nature out there indeed, yet it does not concern me anymore" (D2: 27). When Aili had to give up her plot, she not only lost the land and her deeply felt existential connection with the world, but she also lost the way in which she wanted to live and exist in the world, which was something she had shared with her grandchildren.[208] Aili remarked on this by noting that since she had always been such an active "doer," working and caring for others as well as for her garden plot, being unable to attend in this way had destroyed a big part of her identity (D2: 17).

Aili's relationship with nature also affected her ideas about how her funeral should be done (D2: 31). The first part of the ritual, the actual blessing of the body, was to be performed in the church, in accord with the traditional Lutheran liturgy. She did not want to be buried in the graveyard, however; as she had discussed with her child, she wished to have her ashes put into the soil of their country home. As if to explain why she wanted to be buried in nature rather than in a graveyard, one day Aili brought to the day hospice photos of her favorite landscapes. One was of a forest with a sacred juniper tree and another one was of a blue sky with great white cumulus clouds hanging heavily on the horizon beyond the fields. There was a photo of a beautiful forest pond and another of morning dew on a clear, still lake. The pictures were aesthetically so powerful that it was almost possible to smell the scents and feel the shimmering summer light emanating from them. When I commented on this to Aili, she admitted that she also felt the photos on her skin. She said that every now and then, she would look at these photos, and she would sense them in her body. Aili proceeded to reminisce how she used to make bread from the grain she and her husband grew, and how that process of bread making was so embodied in her. She recalled the different phases of the process which she had learned when just a young girl, the physical labor in the harvesting and how it made her feel strong even when she was only twelve years old. (D4: 26.) If nature and earth were embodied in Aili's memories as a part of her, she also wanted to be part of the soil, after her death, to literally become one with it.

Nature had also been very important to Matti, a retired science professional who was facing death after a quick onset of metastatic cancer. Because of his career, he had dealt with death and serious diseases, and he had a rather materialistic, practical, and stoic attitude toward death. For him, there was nothing enigmatic about it. Furthermore, when Matti's wife had passed away few years before, it had taught him about the "practicalities around dying," as he put it. Matti

[208] This detail came up when Aili told me about one particularly difficult moment. Some time after she had already given up the garden plot, her youngest granddaughter came to her and asked, "Granny, when are we going to the field again?" This question encapsulated so many painful facts about Aili's existential situation at that moment that she almost broke down in front of her granddaughter (D4: 17).

stated that he was not scared at all; he trusted fully in the capacity of medicine to ease his passing in such a way that he could be free of pain. (Matti/1.)

Reflecting back on his life, Matti concluded that he had enjoyed life immensely. Family and work had both played important part in his life—but it was the work that had been a great source of inspiration for him. Matti did not believe in God, although he was interested in metaphysical issues and had read rather widely his whole life. "Buddhism is perhaps closest to my worldview," he contemplated when we discussed this subject (Matti/1). Even if religion was not directly pertinent to Matti, he said that he believed "without a doubt" in the existence of something "sacred." When I asked what he would consider sacred, Matti answered without hesitation, "The birth of a child" (Matti/1). He had witnessed the births of both his children:

> It was, once and for all, a touching and arresting experience; the moment when the baby comes out, it touches… and the first scream. It is just miraculous. (Matti/1)

> When one is able to witness the birth of a child, to witness the beginning of a new life, it is so big of a thing that I believe one cannot really be prepared for it, and one cannot really understand it, until one experiences it oneself. It is so total, something that pierces the whole soul. It is surprising how strong the experience is. An all-encompassing experience (*totaalikokemus*), something that goes into other dimensions (*sväreihin menevä kokemus*)… (Matti/2)

The miracle of the beginning of life—and now, as Matti noted, the end of it—was a source of awe for a scholar who had dedicated his life to studying the boundaries between life and death. In addition to the formation of life, Matti found certain nature experiences to be sacred. One of them which had been especially memorable happened when Matti was on a long kayak trip on a large lake in northeastern Finland:

> We had kayaked already some 80 kilometers and we decided to have a little break right there, in the middle of the open water. I laid down on my back in the bottom of the kayak, and there was the opening of the kayak where you exit the seat. For a long moment I was looking out from that hole at the sky and those clouds, and I listened to the sounds of the water. That was something that stuck in my mind. Very strong… It was an audiovisual experience with a little swinging of the kayak, a very physical experience. I could have stared at that sky forever with the clouds passing by. (Matti/1)

On his travels abroad, Matti found a piece of artwork[209] that simulated the same kind of experience of awe at the sky:

> In New York, in the Modern Art Museum of Long Island City (MoMA PS1), there is a room where one sits and the walls go like this slightly in a cone shape up, and there is a square-shaped opening in the ceiling, and people sit there and look at that sky. That has a little bit of the same… The artist wanted that we would perceive the sky in a more concrete manner… We don't usually look at [the sky] so much. (Matti/1)

[209] This artwork *Meeting* (1980), made by James Turrell, is a specifically proportioned chamber with an aperture in the ceiling that is open to the sky. Following the one he did at the MoMA, Turrell created a series of various skyspaces around the world.

Matti continued by saying that these kinds of experiences are just examples of the sacred, which can be found in many places: “Life has numerous kinds of such spontaneous experiences,” he added. (Matti/1.)

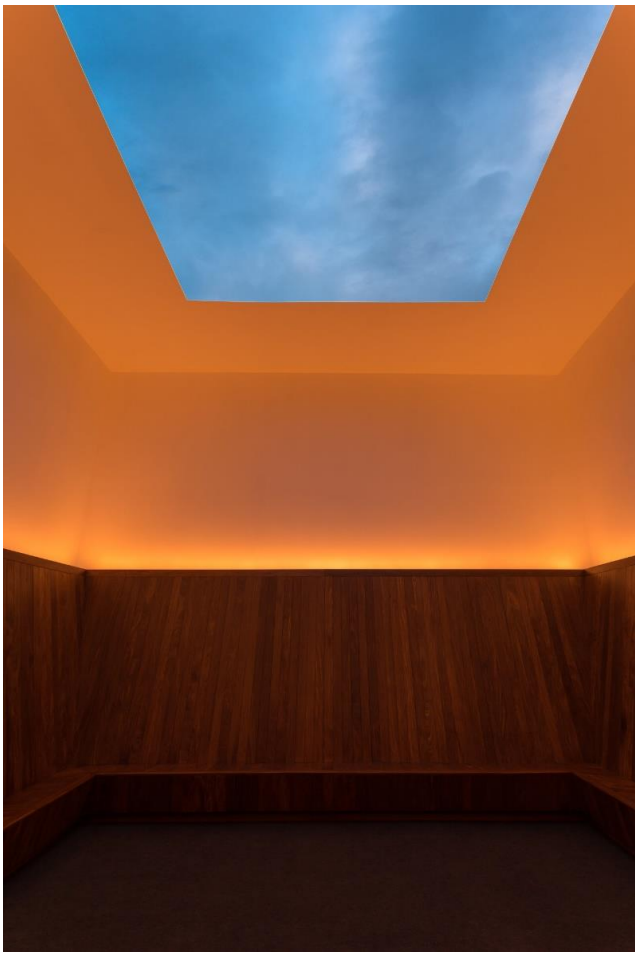

Figure 9. James Turrell, *Meeting*, 1980-86/2016, at MoMA PS1. Photo: Pablo Enriquez/MoMA

Matti elaborated on his kayak story by adding that for him, the appreciation and delight of life culminated in moments like that, “since life is not always that great.” The significance of these kinds of sacred moments increased with time, he said (Matti/2). Since Matti had studied astronomy, I asked him if this sort of experience of the wonders of life had something to do with his work as a scientist, to which he answered:

> Matti: Yes, I think so. If I think of these merely as visual experiences, when I look at the starry sky there is the visual experience of points twinkling in various colors and in various shapes. In the microscope, the visual constellation may be very similar. They are both linked with the certain mystery. We know that there are so many things which we know nothing about; our knowledge perhaps never reaches there. We can speak of the universe and its unfathomable complexity, and the unknown creates the mystery in it.
>
> I: Is it perhaps exactly this exploration of that unknown which has attracted you in science?

> Matti: Yes! It has been exactly the burning drive to seek, and the great joy of finding the truth. Even if it was only the truth of some small sample, the pointing out some biological detail, that revealing of the truth brings a great joy. (Matti/2)

Science was another form of nature to Matti, and it had its own form of aesthetics. For Matti, the experience of participation happened both via aesthetic affective experiences (such as witnessing the birth of a child or having a strong experience in nature) and via scientific thinking and breakthroughs.

Books and other virtual spaces of hope

Aili needed the kinesthetic sensation of being involved with nature, whereas Helena was able to create her connection to nature by visual means. For her, merely the sight of nature felt therapeutic (Helena/1). In both cases, however, we can see the importance of the *sense of connection*, that is, the sense of belonging and being part of something bigger than one's own body. This represents one form of a *virtual space*, which can serve as an impetus for hope and a sense of belonging in moments of crises.

Virtual spaces can also be engendered upon hearing of other people's experiences: Aili often remarked on how she enjoyed hearing about different travel places around the world, and that she experienced and "lived" the stories that the others—mostly volunteer workers—shared in the day hospice (D4: 16). Similarly, one's own memories about specific places could become a source of comfort and consolation. In the day hospital group, this aspect came up whenever there were Karelian evacuees in the group. I witnessed this with Aili but also other Karelians, such as Oiva and Irma, and even with some volunteers with Karelian background. Whereas the "lost Karelia" has become a representation of nostalgia and romanticized ideals of Finnishness, among the evacuees and their families it is commonly acknowledged that the actual area lost to the Soviet Union in World War II was among the most beautiful and fertile regions in Finland (Raivo 2007). Thus, particularly in regard to the land of Karelia, nostalgic memories of the past are significantly entangled with "vanished beauty" and grief.

When Aili lost her community garden and her embodied connection with nature, she found another source of consolation and hope—books. During her whole life Aili had read a lot, but after becoming ill her connection with books grew deeper and even essential to her everyday reality. "Books have kept me alive," she reiterated a number of times (D2: 30, 79). Books became a sort of safe haven for Aili, taking her places where she could no longer physically go. In this way, books literally extended her experience of existence; if her existence used to be mediated via—and nourished by—nature, now it became mediated via books. Books were also a way to process the coming death; in this sense they served as the (ritual) virtual space in which one could practice new solutions and reorient oneself. Every now and then, Aili would come to me with a special poem or a quote from a book that she had been reading. "This is how I think about it," Aili said to me one day, and showed me a page from a novel with a few underlined

sentences. In this instance, after being asked about it by his grandson, the grandfather of the novel was thinking about death:

> The world is nothing else, it is just what it looks like. This I have learned, and beyond that, there is nothing. […] When one is dead, one sees nothing, no darkness; one does not even hear the silence. When one is old, one gets what it takes, that one's got to try to live one's only life as a human. With death and loss one pays for the time, so fleeting that nothing much came of it. That is a high price to pay for an unsellable item. One cannot tell that to a child, nor should one.
>
> "You don't need to think of death. It is in vain. You play and invent something to do, and at night, we will set the nets. I sit in the back, and you row, since you row so well. In the morning, we will go and try the nets; we may get a good catch. Your life is so long that you cannot even realize it. It is summer after summer in a chain without end. When in the autumn one ends, far behind the black, plowed fields, the high snow piles, the crusted spring snow, and birch leaf sprouts, already the blue light of summer shimmers, again and again. It won't dim, it won't burn out," grandfather said.[210] (Pentti Lassila, *Armain aika*, 134–135)

When reading these lines, Aili said, she felt that the author was expressing her views about life and death. Without trying to know what exactly Aili's thought process was around this, one could nevertheless see that there was a kind of double story here. One was the grandfather's rather nihilist account of what happens after death, "One sees nothing, no darkness; one does not even hear the silence." On the other hand, there were the delightful moments with loved ones, the eternal cycling of the seasons and generations—life goes on. However Aili interpreted these lines, this account illuminates how for her the participation was not merely a way of experiencing and sensing the reality, it was also a significant way to reorient oneself by facilitating a new, relevant, and even metaphysically meaningful understanding of one's personal life situation. In my study, I have called this sort of participatory engagement *aesthetic experience*, since "aesthetics" represents the common element in all the experiences of art, ritual, and landscape or nature which my research participants told me about (Butters 2016).

10.3 Aesthetics as participatory experience

Aesthetics and aesthetic experience

When orienting aesthetically to the world, there is no evident epistemological or metaphysical dissonance (with scientific orientation), yet aesthetic experience evokes creative space (Kapferer's ritual virtuality), saturated by imagination, in which a person is able to *participate*

[210] "Maailma ei ole mitään muuta, se on vain se, miltä se näyttää, sen minä olen oppinut, eikä sen takana ole mitään. […] Kun on kuollut, ei näe mitään, ei pimeyttä, ei kuule edes hiljaisuutta. Vanhana tajuaa, mitä se maksaa, että sai yrittää ihmisenä elää ainoan elämänsä. Saa kuolemalla ja häviämisellä maksaa siitä lyhyestä ajasta, josta ei paljon mitään ehtinyt tulla. Se on korkea hinta epäkurantista tavarasta. Sitä ei voi lapselle sanoa, eikä pidä sanoa. – Sinun ei tarvitse kuolemaa miettiä, se on turhaa. Leiki sinä ja keksi tekemistä, ja illalla lasketaan yhdessä verkot. Minä perässä, ja sinä soudat, koska sinä soudat niin hyvin. Aamulla käydään kokemassa verkot, voidaan saada hyvä saalis. Sinun elämäsi on niin pitkä, ettet sinä osaa sitä edes käsittää. Se on kesiä kesien jälkeen ketjuna, jolla ei ole loppua. Kun yksi päättyy syksyyn, etäällä mustien kynnöspeltojen, korkeiden kinosten, keväthankien ja koivun hiirenkorvien takana kajastaa jo kesän sininen valo, uudestaan ja uudestaan, se ei himmene, ei se sammu, isoisä sanoi." (Pentti Lassila, *Armain aika* 134–135.)

affectively with the world. Aesthetics is not always about beauty, and in regard to nature, for instance, it can actually take rather cruel and somber forms. The following account by Heidi was the one that pushed me toward thinking of the meaning of aesthetics for my research participants, especially in relation to *metaphysical thinking*. We had had a long conversation, which remained our last, because soon after this meeting Heidi became unable to communicate verbally. At this point, Heidi was bedbound and very fragile, yet still alert in her mind. I was just about to leave from our meeting when she suddenly called me back: "There is something I still want to share with you," she said, "just in case, we don't… you know." She did not need to finish the sentence, since I understood what she meant. Heidi began telling about an incident which had occurred already months before her condition worsened. I hastened to turn on my recorder:

> I was babysitting my grandson at my house and I was just putting him down for a nap when I heard this sound from the front yard. A rustle of some kind. The dog was alerted by the noise also, so we went downstairs to see what was going on… There was an accipiter… a hawk, which was eating a blackbird, right there in my front yard!

Heidi had taken some pictures of the scene with her phone and now she was showing them to me. Then she continued:

> When my son arrived an hour later or so, he looked [at the yard] and asked in awe, "What on earth has happened?" You see, there were black feathers all over on the white yard, there was snow, you see. They were there for many months, those black feathers, and pieces of bones and the head and everything.
>
> I thought by myself that… and at that point, it actually palliated me greatly that I imagine that I am myself that blackbird that the hawk comes to eat… that I am going along into the cycle of nature. It felt very… I felt good, it felt like a gentle thought. […] It made some sort of an indelible impression on me, indeed, this scene. (Heidi/2)

After telling this, Heidi went on explaining how nature, and especially birds, had become very meaningful to her as she had gotten older.

There listening to Heidi, I sensed that she was sharing a very meaningful memory. The story seemed to involve a sort of turning point or revelation for Heidi. By looking at the dying blackbird, she had understood that she would die from her cancer—yet it was all fine, as this meant that she was part of nature, part of the universe, and that was where she would return. There was an obvious analogue between her and the bird. Like many cancer patients, she perhaps had experienced the tumor as something that was attacking her. Nonetheless, I wondered why this particular incident was so important to her that she had made a point of sharing it with me, literally as her very last words.

The philosopher of aesthetics Ronald Hepburn (2004: 127) writes that aesthetic scenes may sometimes be experienced as "revealing something fundamental (and no doubt grim) about how things really, or ultimately, are." In Heidi's case, her experience was both apt and poignant in terms of "how things ultimately are." Despite being "grim," as Hepburn puts it, Heidi's

experience was described in a way that did not include any negativity—rather quite the opposite. The experience was "palliating" to her, and the idea of returning to nature—perhaps curiously so—was "gentle." Reflecting on Hepburn's words and Heidi's story, I started to realize that I had heard similar accounts from other research patients in which an aesthetic experience had led to a realization about their existential situation. Some of these experiences were actively sought after (for instance, by means of reading poetry or a novel, like in Aili's case), but they also occurred quite randomly and by chance, causing deep impressions. As seen above, nature was a major source for these impressions, yet these moments were inspired by a variety of sources: visual arts, music, literature, and even dreams and visions.

This sort of aesthetic appreciation infused with metaphysical realizations is something that Hepburn (2004: 127) calls "metaphysical imagination." Since it was precisely with the help of these experiences that some of my research patients were able to not only make sense of their existential situation but also create their personal metaphysics, I have called this "metaphysical meaning-making" (Butters 2016). Patients did not always find a certain meaning in these experiences, but they could at least *imagine* and *think about* metaphysically meaningful things, and that was what made all the difference.

In the context of aesthetics, imagination functions as the virtuality (Kapferer 2006), since the word 'virtual' refers simultaneously to something fictional and illusory as well as to something with the potential capacity to enrich and enhance reality. Different forms of art, as well as (religious) ritual and environmental aesthetics (as in a landscape or a single element of nature) enable the creation of virtual space for learning, absorbing, tolerating, and even celebrating tensions and paradoxes of life. In the virtual space enhanced by art, ritual, or nature, things otherwise impossible become possible; through the ritual frame, one enters a virtual "as if" world of possibilities. Wherever the element of aesthetics was present, it seemed to work as the mediation through which time, life events, emotions, and types of affect were reorganized in a creative, meaningful manner. Here, the human "experiencer" was not just "ontologically related to an environment or to a world" (Ihde 2009: 23) but also aesthetically so.

Dewey ([1934] 2005: 222) defined art as "a quality of doing and of what is done." Seen in this way, art is a quality that can be found in various places and acts, and this is how my research participants tended to refer to art as well. Some never talked explicitly about "art," but simply made references to certain novels or poems, for instance, which had caused them to engage in metaphysical thinking in regard to their situation with a terminal illness. Like medicine, aesthetics was co-constitutive to patient's identities, which they were constantly adjusting in relation to their environment. For instance, my mother spent a weekend at our summerhouse, making a point of listening to all of her jazz LPs. In addition to the music (which she loved), the act of listening was intertwined with her memories, and, in fact, with her whole life history. All of the records related to certain points in her life, so listening to them was like going through a photo album with some of her most important moments. Aesthetics can facilitate ritualized

remembering, which in turn can aid in constituting the new identity of a dying person; contemplating the personal history that leads to the present moment may provide a certain order to the often chaotic situation of illness (see also Quartier 2010). Ritualized remembering makes the concept of time more tangible, and it may facilitate the thought of the end of life. It is also an effective way of saying goodbye to people, places, and times in one's life.

Metaphysical meaning-making and aesthetics

Based on the phenomenological understanding of human experience, I suggest that it is precisely the corporeality and sensoriality of aesthetics that makes it so powerful and able to bring insight, not just affectively but also cognitively.[211] This view was apparent in many of the accounts I heard, but Martti's story shows well how his entire body was affected by the aesthetic experience.

Martti was a former teaching professional in his sixties, whom I met on the oncology ward. The first time I interviewed Martti, we talked about his sentiments surrounding his diagnosis. I was asking how it had affected him, his corporeality, and… "And mortality?" Martti finished my question and launched into a story. In the very beginning, when his cancer diagnosis was not yet confirmed but strongly suspected, he was driving to the hospital for an ultrasound. This test was going to be telling in regard to his diagnosis, and thus it was a very important appointment. While sitting in his car, Martti was listening to a radio show on classical music. John Tavener's "Eternal Memory" (1991) came on the air and, all of a sudden, Martti had a strange experience.[212] Upon hearing Tavener's music, he had a vision. The music permeated his being and "went deep into the soul" as he explained, transporting him "into heavenly spheres" (Martti/1; Martti/2). Instead of sitting in the car, he saw himself outside in a beautiful green landscape, standing there in the green pastures with still waters. "It made me feel very good," Martti explained. He continued that while being there, he realized that it was all okay, that "this afterlife isn't such a bad alternative to this world. I have seen this already for sixty years, so this is okay" (Martti/1). The vision was perplexing in its vividness, Martti concluded, and thus it made a strong impact on him; indeed, it seemed to color his whole illness experience, pacifying and consoling him. He kept referring to it numerous times over the years I knew him. The experience was powerful, he explained, because ever since that moment he knew that "there was nothing to worry about. I was either going to be cured—or, if not, I was going to be with God. There were only two alternatives—and they were both good ones" (Martti/2).

Martti believed in God, and he was part of the Lutheran revival movement of Conservative Laestadianism. Given his conviction, it was perhaps not surprising that he felt so confident.

[211] My perspective has been influenced by Mark Johnson's book *The Meaning of the Body* (2007), in which he argues for the theory of the *embodiment of human mind and meaning.* He claims that as the mind emerges from and co-evolves with the body, all human meaning, understanding, and reasoning are embodied activities. Among the various embodied experiences, Johnson stresses the importance of aesthetics for human understanding and cognition (Johnson & Lakoff 1999; Johnson 2007).

[212] See https://www.youtube.com/watch?v=ENiwvkU5yZM.

However, it was neither the word of God nor prayer that induced his vision. Instead, it was music, an auditory aesthetic experience, which engendered the aesthetic experience in the form of a revelation of paradise. Later on in our conversation, Martti connected his vision with the famous passage in Psalms: "He makes me lie down in green pastures. He leads me beside still waters; he restores my soul" (Psalm 23:2–3). Martti's account exemplifies how a sensory experience served as fuel for a spiritual epiphany, and how meaning-making can happen through the intertwined aesthetic connection of the inner (subjective) reality and outer (objective) reality.

Compared to medicine, aesthetics offered an alternative affective environment in which one could weigh and contemplate one's situation. In contrast to medical rituals, in which "things were done to the body," in the personal rituals described in the previous chapter the body became more of an active subject of experience. Through engagement with aesthetics, the body as an active subject seeks to make sense of its experiences on its own terms. In this way, both ritual activities and aesthetics can become *forms of inquiry* and a *source of knowledge* about the world (Jennings 1982; Schilbrack 2004: 135). In personal rituals such as writing, the ritual itself becomes an open inquiry about the way things are (Raposa 2004: 123), and realizations happen via the body of the ritual participant.[213]

If Martti was impressed by music and a vision, Oiva found inspiration from scenery in the real world. I had learned to appreciate Oiva's creative outlook on life; he always seemed excited about something, and his life story (which he loved to share) was filled with the most incredible endeavors and colorful events. Now, however, Oiva was slowing down, losing his mobility and vision. Even after being told that it was probably only a matter of days, being severely ill and so close to death, he was still happy to talk and share his thoughts with me. During our last meeting we were talking about his funeral wishes, when he was suddenly taken by a memory of his wife's funeral some years before (Oiva/2). "Now this image came to my mind. Of that situation," Oiva started after a small pause. Oiva's wife had been cremated, and Oiva went to pick up the urn with his son in order to have it buried in the cemetery. Oiva continued speaking, but then the pace of his speech slowed: "There were only me, my son, and that cemetery worker who showed us the place. […] The picture that stayed here (pointing with an index finger to his temple) was that… When…" Oiva was getting very emotional and he could barely continue talking, "When my son was born…" Oiva now began openly crying, and I consoled him by

[213] Many artists throughout the ages have described moments of epiphany. For example, Virginia Woolf wrote about "special moments of being," moments that clearly stand out from the usual state of "non-being," by which Woolf means our unconscious manner of drifting through life (see Tuohimaa 2004: 88–89). Woolf sees that there is a meaningful tapestry behind the ordinary, and she calls the whole world "a work of art." The moment when one is capable of recognizing this is the exceptional moment (Tuohimaa 2004: 88–98). While her description is not very different from mystic accounts, Woolf very clearly states that for her it is not a matter of God but life itself as art. Hence, aesthetics and the aesthetic attitude can be akin to spirituality or religion, yet different, since aesthetics lacks moral or dogmatic claims (Krohn 1965: 72). This sort of appreciation toward even the simplest forms of life can be found in some of the special moments that my research participants shared with me.

putting my hand on his shoulder. In the eight months I had known him, I had never seen him emotional like this. After a while he continued talking:

> My wife was carrying the baby like this in her arms, bringing him home… Now, there was the son carrying his mother in his arms… in the same size package… It was a very touching image (*näky*) and a metaphorical image, so later at home, as soon as I got home, I drew a picture of it. (Oiva/2)

Oiva told that he had never shared this intimate, symbolic drawing with his son. This memory, involving the most beloved persons in Oiva's life, had taken the form of a mental picture, which he had used for the creation of an art piece. His aesthetic vision had captured the cycle of birth and death, literally depicting the metaphysical condition of our existence. I believe that this was one reason why Oiva shared the memory with me, right then, on his own deathbed.

Although we had met numerous times, Oiva seldom got very emotional. Because this time it was different, toward the end of our conversation I asked him if the end of life had led him to give up on many things. He answered, "Hell no! There's no point in giving in before the fact!" (Oiva/2). If it was not typical before for Oiva to dwell in the thoughts of his coming dying too much, now it seemed that by sharing the affective memory about his wife's funeral, he was seeking to make sense of his own mortality. Through aesthetics, which here appeared as a mental (virtual) image and a created art work, humans can make and experience meaning (Johnson 2007: 209).

Living and dying as art

Much like Oiva, Inkeri also displayed a rather passionate approach to life, but unlike him, she extended her attending curiosity to death and dying as well. I have earlier referred to her writing project regarding her diagnosis (Chapter Five), but prior to this Inkeri used to do sculpting, in which she combined metaphysical thinking and philosophy with tangible artwork. When Inkeri explained her creations to me the first time, I could not quite understand what she meant by her "projects," but once I visited her home and saw the actual pieces of furniture that she had built as part of the "castle of her mind," I started to understand what she had been talking about. The most important events and beliefs of her life (e.g., the birth of her child, her spiritual thinking) were symbolized and built in the solid form of furniture and embedded in the detailed decoration of her home. Inkeri actually referred to her home as her "private mythology," and as such, it was "a very important place" (Inkeri/2).

Inkeri defined herself as a spiritual person interested in mysticism. The way in which form and content, material and immaterial, and ultimately life and death came together was something that interested her greatly. She called this the "philosophy of the 'AND.'" "It is about this AND that, always, the polarities come together" (Inkeri/1).

Inkeri's "everyday art" became evident to me when she invited me for lunch one day at her home. Everything from the food and the wine, the desert, the setting of the table, even the colors of the napkins—all of it—was carefully planned and designed. It was more than just a lunch.

Since it was clear that Inkeri was near the end, sharing a meal and some wine was an occasion that we both definitely recognized as special. Before I left, Inkeri gave me a gift of fine sand, which she had collected from a holy place on one of her travels, and three small votive candles. She did not comment on or provide any guidance with her gift, but I gathered that it was meant for a special occasion during which I would remember her.

During the lunch, we talked about Inkeri's final project, which was not merely a notebook but a kind of a blueprint that essentially represented her life—and her death. The layout of the contents was arranged in the form of a house instead of a traditional list-like table of contents. A timeline ran through the mid-section, and the surrounding sections represented her home both literally (as I was able to testify, having visited her house) and symbolically, since in fact she had designed her home to reflect her inner reality.[214]

OFFICE Work-related things Creativity Excitement	HOME CATHEDRAL Life mystery Philosophy Teachers	LIVING ROOM Art & art pieces
PAST LIFE Stuff, letters, pictures Anxiety and burdens Multiplicity Is it all just going to vanish?	HERE AND NOW Loved ones Friends Terminal illness Care plans	*GATE TO THE COMING* *Plans and dreams (treatments!)* *Testament* *"Beauty before all"* *Last Frame*
KITCHEN Good food Beautiful setting Everyday rituals	HERMITAGE A hut of a hermit Sleep, rest, dreams Books	BALCONY Plants & the miracle of growth Morning glory, herbs

Inkeri was excited to share her writing project with me. This is how in her notebook she described our working together:

> In addition to the good nurses and volunteer workers, there was a special surprise waiting for me in the hospice home: Right at the first time there was also a researcher, Maija Butters, a cultural anthropologist, who presented herself and told that she was doing a doctoral dissertation on palliative patients and their worldview and their emotions in regard to facing death. Already our first meeting aroused joy in me, and excitement to share my experiences and to become a part of her research sample. […]
>
> Being a part of this study has brought a completely new dimension to the hospice home, since in this way it becomes about something more than just about unidentified fear and anxiety for the expected hospice care. Exactly through those research interviews, I have gotten new tools to encounter and approach the "inevitable"—the end of the journey on this earth. (Inkeri, *Since one could even die from it*, p. 13)

[214] I have taken the liberty of simplifying her model a little bit. All the "room" names (the main sections) are as in Inkeri's notebook, but for the sake of anonymity I left out a few of the contents of the boxes. Inkeri sent me the whole notebook prior to her death, and she gave me permission to use it as well as any other materials (such as pictures) that she had given me. I had the impression that she was quite pleased that her artwork would make it into my study.

Once Inkeri was able to start writing about her situation, she took a title to work on every day. The hardest title to engage with was in the section called "Gate to the coming" (in italics). About six weeks before she died, she was able to get to the final part, "Last Frame." Inkeri went to the National Library of Finland in order to write there. The library had just been renovated, and she sent me a text message commenting on how gorgeous the environment was, and how wonderful it felt to be able to be there writing. Even at the risk of putting words into her mouth, I asked her in my text reply if she would describe the environment as "sublime." She wrote me back, "Yes! That is exactly what it is!" This is what she wrote under the title "Last Frame" on that day:

> The "image" of this title got its impetus in a park, where I was sitting with Tuija on a bench out there and we talked about something related to funerals. There was a flower bench close by and there were blue irises growing there. There I got a vision of my own "frame" for my last journey, that is, a revelation of my own funeral. The symbol would be "my shape of" cross with a golden center where my monogram would go. The actual limbs of the cross would be made of the blue flowerings of IRISES. The vision has since sharpened, and many of the details are filled now with "wishes" which I would like to express to my loved ones "in time."
>
> Writing about this has proven to be difficult, however. It has also become a difficult topic to speak about, and I have not expressed my thoughts to really anyone else than to Tuija during our writings retreats. Last autumn, when I got the referral to the care of hospice's home team, I got even more impetus to keep this idea (with its wish-list) hidden. It felt that if I tell about it, it [death] will happen right on the spot! (Inkeri, *Since one could even die from it*, p. 23)

The Last Frame referred quite literally to Inkeri's funeral (i.e., to her personal last ritual frame). Inkeri wanted to plan every concrete detail involved with it, in order to personalize the ritual to her liking. Inkeri felt that the surroundings of the National Library, where she was penning the text, eased the difficulty of writing. It was simpler there to find the words to express herself:

> This place [the National Library; see Figures 10 and 11] is nothing less than a solemn stage to express something that is constantly in one's mind but which is so difficult to "pronounce." Here one is able to catch again the sensation that some guidance directs the way things happen, and everything that happens is a definite part of this story. Hearing the inner voice and following its guidance will make things happen exactly the way they are supposed to. (Inkeri, *Since one could even die from it*, p. 24)

After this, Inkeri goes on describing in great detail how the "last frame" ought to be done: a flowing arrangement with a sculpted middle part, which Inkeri had already made. She guides her florist friend on how to make the final frame correctly, and then adds:

> The IRIS cross would go beautifully on top of the coffin. I would like it if the flower cross would be then taken along to the memorial and put on the table as kind of a sign of my presence. For flowers I wish that everyone who wants to brings a single white flower which would then cover my coffin; also those flowers could be gathered and brought to the memorial as decorations. In this way the mere coffin, decorated with a cross made of "earth dust," would start its journey toward the crematorium. (Inkeri, *Since one could even die from it*, p. 25)

After writing all this, Inkeri continues for few more pages with additional details for the funeral, including the music she wished for and a guest list of people whom she would like to invite.

It becomes clear from Inkeri's text that it was challenging to start and keep writing about the situation. Much like with Marjo-Riitta with her blog (see Chapter 9), writing seemed to make it all more real and could even cause things (i.e., death) to happen. Here the ritualized manner of writing in the special frame of the National Library eased the difficulty and supported her.

Figures 10 and 11. The National Library, Helsinki. Photos: Maija Butters.

Being able to write her booklet, she was able to process her situation. In other words, by doing this project, which described not only her sentiments about her situation but memories of the past and ideas and thoughts about life in general, as well as plans for the future (for the coming funeral), Inkeri was able to assume the task of making preparations.

As noted on multiple occasions in this study, ritual often functions as an attempt to control and striate the randomness aspects of life. Inkeri's careful efforts to manage all of the details relating to her funeral can be seen as comprising attempts to take control over her own mortality. As she had emphasized during her whole illness trajectory, she wished to practice her agency until the very end—and extend it even after that. In the text, she makes a wish that the iris-cross would be taken along to the memorial and put on the table as "kind of a sign of my presence." By carefully designing various symbolic details of the funeral, she "owned" her death and gave

it her identity; she even managed to declare her agency and assert her presence in the memorial in the form of the iris-cross.

Overall, writing was Inkeri's manner of practicing acceptance. It was not just the act of writing, however, but the whole project—which included the decoration of the booklet, the process of naming it, and in the end the fact of sharing it with me, and her family and friends—that was necessary for Inkeri to feel "ready." The booklet itself was not just a notebook or a private diary but Inkeri's last artwork, which she wanted to share with others.

When Inkeri approached death, she was moved to the hospice ward. She called me, and I promised to go and see her later on that day. In a few hours, however, she called me back and told me that she felt very tired and was thinking of getting some sleep, so I should come only the following day. That night Inkeri died. The next morning, I drove to the hospice home to learn that she had just passed. Since the staff knew that we had been close, they asked me if I wished to help in washing her (the family members had already been asked but they were not able to come). It was my reciprocal gift to Inkeri, I thought. Afterwards we put her back in bed for her family to say their final goodbyes. We found one of her beautiful silk scarfs, blue like her beloved irises, to put around her neck. There was a bouquet of colorful tulips and a white candle on the table. It was perfectly serene and beautiful, exactly the way Inkeri would have wished, with "beauty before all."

In the lives of my research participants, aesthetics was a way to enjoy life and to enhance and enrich everyday reality. Yet, as seen with research patients such as Helena, Martti, Aili, and Inkeri, aesthetics can also transform into ritualized practices by means of which one can think about and work with reality. Ultimately, aesthetics can become practices to enhance one's authority and agency in a situation where other ways to create change are diminished.

Aesthetics—art, nature, and ritualized practices in relation to one's body, for instance—played a significant role in patients' lives. Here Inkeri's account exemplifies exceptionally well what kind of asset an aesthetic orientation to the world can be for a person. In a way, her everyday reality was a constant performance in which she created herself and her surroundings (to the extent that it was possible) according to her wishes and needs. Inkeri's enthusiasm to also study death and dying (by attending some of the same seminars and conferences that I did, for instance) was not always understood by everyone in the day hospice group. For Vivian, it was a horrifying idea that one should have death as their hobby, as she put it when commenting on Inkeri's interest in dying (Vivian/2). But for Inkeri, this was an empowering thing to do, to learn and to assert authority over her own situation.

There is a specific reason why I have written so extensively about the various sorts of aesthetic moments and engagements that my research participants had—whether they were people with artistic tendencies or people without any special connection to the arts. Of all of the accounts that I heard from my research participants, the ones involving aesthetics were the most affective and empowering for the patients themselves in regard to their emotional and

existential challenges. Research participants such as Kimmo, Heidi, and Vivian told me about hard moments during their illness trajectories, including fears and anxieties, which had threatened their self-identity and caused depression. To counterbalance these experiences, many sought things that would help them—help them feel better, help them relieve their anxiety, and perhaps help them come to terms with their situation. Even if one had a relatively unproblematic attitude toward death and dying, as Eeva and Aili seemed to have, there was still often a need to achieve understanding about the approaching death or to seek some sort of closure around one's ending life. Personal rituals and ritualizations, as well as aesthetic engagements and experiences with the world, offered the research participants that kind of relief and palliative help. And at times, they induced metaphysical or existential insights about one's situation, which could be grim but simultaneously reassuring. Art and nature gave practical tools to the patients to work with their feelings of loss and closure. As a mode of participation, aesthetics offered "phantasmagoric space" (Kapferer 2006) in which one could reorient and re-structure oneself (Williams & Boyd 1993, 2006). Ultimately, aesthetic creative practices brought to patients Spinozian *laetitia* and *potentia*—joy and capability—which increased their ability to handle their situation.

PART V – CONCLUSION

11. DISCUSSION

11.1 Summary of the research questions and overview of the analysis

Summary of the research questions

In this research, I have studied how a small, defined group of Finnish palliative patients[215] approached their end of life after being diagnosed with serious illness leading to death. My overarching research question asked how contemporary urban Finns who have been diagnosed with a terminal illness experience and negotiate their end of life, death, and dying. Further research questions had to do with language, environment, and practices around death and dying. The first sub-questions asked how palliative patients talk about the end of life, what kind of language they use, and what kinds of imageries they have in relation to death and dying. The second one inquired how the research patients were affected by both actual and virtual places and spaces, especially in regard to augmenting or diminishing their agency at the end of life. Finally, the study explored what happens around patients once they are in palliative and/or hospice care, and especially what kinds of rituals exist in relation to death and dying in Finland today.Overall, I wanted to understand the experience of being seriously ill and facing death, how my research patients oriented in the vicinity of death, how they negotiated their end of life, and what kinds of tools they had in their use to handle their situation.

In order to find answers to my research questions, I conducted fieldwork among palliative patients for four years in 2014–2017. Due to the complexity and subtlety of my research theme, it was methodologically necessary to immerse in the field and spend time with the research patients by discussing, conversing, and listening to their accounts instead of simply doing a series of structured interviews.

Through an ethnographic approach which emphasizes lived experiences and subjective interpretations of reality, I have built an understanding about the everyday life of my research patients, including the variety of relationships which these patients had at the end of their illness trajectories, and how these constructed and affected their end of life. The phenomenological approach used in this study highlights the embodied and embedded aspects of human experience, not merely in regard to the social reality but also in relation to materiality, time, and space. Furthermore, introducing critical mediated posthumanism as well as Bell's ritual theory into the phenomenological analysis enabled an examination of aspects of cultural processes, which at times involved distributed agencies via technologies and medical practices as rituals.

By combining two different kinds of approaches in the research material—phenomenology, on one hand, and critical mediated posthumanism and ritual theory, on the other—it was possible to gain a fuller, more informed understanding of the possible experiences of dying in

[215] The research group represented a very specific sample, since almost all of the participants were patients in a hospice home. This is not the case for all dying Finns.

contemporary Finland. This kind of "tandem approach," which combines another analytical perspective with phenomenological analysis, is common in contemporary anthropology. In a study such as mine, which is mostly constructed around the phenomenological analysis of subjective experiences, the critical perspective offered by mediated posthumanism and the anthropological theories of ritual illuminate the larger social and cultural structures and dynamics involved in these situations. As Desjarlais & Throop (2011: 95) point out, "analytic approaches that do not consider the place of the subjective or intersubjective, or of experience or consciousness, in cultural or political realities are missing out on something."

Overview of the theoretical analysis

I based my analysis on the conceptual understanding of a patient as a relationally constituted and mediated subject, living and dying in an affective relationship with their surroundings. Due to the embodied and embedded nature of subjectivity, I paid close attention to various affective structures, practices, and environments, as well as the human and non-human relations in which the patient was involved. Through the discussions, interviews, and my ethnographic observations, I started to slowly build answers to my original research questions, which became more nuanced as time went on. I formed my analysis around three themes which emerged from my research material. The first relates to issues of place and space in a concrete and metaphorical sense (Part II); the second one relates to institutional rituals (Part III) ; and the last theme concentrates on personal rituals and the meaning of aesthetics as participatory practice (Part IV). These different sections benefited from different theoretical tools. Even if I have utilized various theoretical approaches, my analysis remains on the micro level; this was a conscious choice affected by my overall phenomenological orientation to the research.

To apprehend the emotional, social, and physical situations in which my research patients found themselves—and which intertwined and affected their experiences, hopes, and fears—a multifarious analysis was necessary. Typically, phenomenological analysis focuses on the lived body (Merleau-Ponty [1945] 2005), that is, the sensory body, which perceives, experiences, and senses life—and, in this case, also death. By carefully listening to what my research participants said and how things were expressed, I was able to learn about their embodied perceptions, interpretations, and understandings of situations. When analyzing the spatial issues, which arose in the discussions with the research participants, I profited from Tuan's phenomenological perspective on space and place, and how people related both to the various spaces they encountered during their illness trajectories and to those places and spaces they longed for. By adding the posthumanist perspective to the analysis, I was able to look at how different materialities in various places affected the patients, and how the material environment as well as biomedical practices became constitutive of their experiences, and at times very concretely mediated their end of life. Furthermore, ritual theories illuminated well how the lived body became also the culturally, socially, and environmentally shaped "Foucauldian" body, which moved along the care trajectories, encountered medical staff, and received medical

treatments. The embodied experiences can be analyzed as objectifying or subjectifying, thus making the body a multiplicity; this becomes particularly salient and tangible in terms of what Feenberg (2006) calls the dependent body and extended body. In this way, it was possible to distinguish different positions of the patients' multiple bodies, and how these various positionings affected their experiences of the end of life. In actuality, one can be a little bit of everything (subject, object, vulnerable, empowered, etc.) even in a single situation, and thus these categories exhibit dynamic crossover. However, keeping the multiplicity of the body in mind makes it possible to form a fuller and more nuanced understanding of a dying patient's lifeworld.

Throughout the study I refer to Spinoza's theory of emotions (in the way in which recent philosophers and new materialists have read him), in which he links the main emotions of *laetitia* (joy) and *tristitia* (sadness) to the human capacity to act and think: joy increases one's ability to act, whereas sadness decreases it. Spinozian monism accords well with philosophical approaches that emphasize relationality and the embodied materiality of human experience. Through the Spinozian manner of interpreting affective situations via joy and sadness, one can approach a situation in terms of its effects; in this way, the specific situations that my research participants encountered could be gauged in terms of whether they caused an increased or decreased ability for them to think and act. The Spinozian manner of seeing power as twofold—*potentia* as empowering and *potestas* as restricting and controlling—illuminate well the double nature and twofold possibility of every encounter. I was interested in finding ways in which palliative patients were empowered in the face of death in order to achieve as much authority over their dying process as possible.

When discussing about rituals involved at the end of life and dying, it was possible to separate institutional (often objectifying) rituals, which were imposed on palliative patients by various care locations, and personal (often subjectifying) rituals, which were initiated and practiced by the patients themselves. In regard to the institutional rituals related to the processes of living the end of life and dying, I employed especially the ritual theory by Bell, who sees rituals as processes in which power relations and interpretations of reality are rehearsed, imposed, negotiated, and, at times, contested. In terms of analyzing personal rituals and ritualization, I profited from the theorizations by Asad, Kapferer, and Schilbrack, who all—in their own ways—emphasize rituals as ways to learn and adopt thinking and performing in life (and death). Furthermore, from a societal and structural point of view, rituals can be perceived as Deleuzoguattarian striations seeking to organize chaotic, smooth phenomena, such as dying. How rituals worked for the patients themselves depended greatly on the authority and agency in the ritual. Thus, who "owns the ritual" became an important question. Again, it is possible to utilize the Spinozian concepts of *potentia* and *potestas*; those rituals and ritualizations which supported the dying to augment their authority over the situation, thus bringing them *potentia*,

were the most useful. But when rituals were designed first and foremost to serve some other actor in the situation, rather than the patient, their effects could become more challenging.

Somewhat similar to the conceptualization of striated and smooth by Deleuze and Guattari is the classical division of causality and participation used and developed by anthropologists for nearly a century. The difference between these conceptualizations is that striation and smooth describe overlapping and ever-changing dynamics of almost any imaginable process in reality, whereas causality and participation function as more strictly defined ways to "orient toward the world" (Tambiah 1990), or even "tendencies of the human mind" (Hanegraaff 2003). Thus, the latter conceptualization seems to be psychological, describing subjective orientations to the world instead of describing reality *per se*; hence, it can be seen as very different from more philosophical accounts of how reality works, such as presented by Deleuze and Guattari. The disjunction between these perspectives does not need to pose a problem, however. As discussed above, the analysis has a "tandem approach," in which the (traditionally regarded) subjective phenomenological perspective is studied together with the (traditionally regarded) objective perspective in the form of ritual theories and the critical mediated posthumanism. Furthermore, the separation of the subject (inner) and the object (outer) echoes the kind of dualistic approach which this study deems impossible—both the phenomenological and posthuman approaches agree on this.

The conceptualization of causality and participation described different kinds of orientation among the research participants in relation to their end of life; causal orientations emphasized medical interventions whereas participatory orientations were concerned with various activities that for the patient brought about a sense of connection. Many meaningful activities related to hope and a sense of completion could be defined as participatory by their nature. One of those was aesthetics, which proved a meaningful tool to negotiate issues of the end of life, death, and dying.

11.2 Research findings

Key findings

Regarding my overarching research question of how terminally ill Finns experience and negotiate their end of life, death, and dying, I have found that the experiences of my research participants were strongly mediated via medicine first and foremost, but negotiations also happened through personal rituals and aesthetic expressions. This answers also the first sub-question about what kinds of language and imageries were used when research participants talked about mortality; medical language was used in order to handle issues regarding the end of life. The moment of death, if mentioned at all, was often talked about in medical terms (in terms of sedation, for instance). Most of the practices in which the research participants engaged at this point were related to medicine (i.e., various kinds of medical treatments, check-ups, laboratory visits, tests) and, of course, pharmaceuticals, which composed an important element

of the end of life for many. The whole illness trajectory, with its various medical encounters, strongly affected the way in which the research participants felt about their current situation, and how empowered they felt in regard to it.

The next sub-question concerned the importance of the environment for my research participants—if place mattered and how different spaces and places affected them at their end of life. The findings regarding this are strongly intertwined with the other findings about language and rituals. The meaning of a place—whether actual or virtual—was linked with the place's perceived ability to either augment or diminish the patient's (sense of) agency in regard to their attempts to negotiate their end of life. Some places, such as summerhouses or certain nature spots, were empowering and existentially meaningful in themselves, and thereby enabling and facilitating personal meaning-making processes in the face of death. In turn, the relationships and encounters that the research participants had with their various care places were experienced as either empowering or disempowering. Perhaps it was not surprising that in those places in which the patients had experienced themselves as seen and heard as whole persons with their wishes and worries, they had felt safe and more able to negotiate and face their challenging situation. What was striking, however, was the way in which past negative encounters in medical surroundings had a long-lasting and disempowering effect on the research participants in regard to their present sense of safety and experience of agency. The vulnerabilities that illness brings are not merely physical but also psychological, social, and deeply emotional, and they seem to greatly affect the way in which seriously ill patients encounter their surroundings.

The medical mediations that I found, both in regard to language and practices, were actually often about the extension of life, that is, about survival rather than death and dying *per se*. However, medicine was not the only means by which the end of life and dying became mediated and negotiated. Certain research participants created personal practices—rituals and ritualizations—some of which actually helped to approach death and dying in an empowered manner, whereas others were aimed more at avoiding death and averting dying. I have classified these accordingly as rituals for preparation for death, on one hand, and rituals for avoidance of death, on the other. This responds to the last of my sub-questions related to possible rituals at the end of life. It was through these rituals and ritualizations that patients were able to negotiate—to think about, to handle, and to concretely act in—their situation and the pending future. Especially those rituals and practices which engaged aesthetics in one form or another became meaningful and even powerful tools to comprehend the end of life and find solace in it.

Next I will continue to a more detailed explanation of the findings of the study, of which the first has to with the embodiment of existential concerns.

Embodied experience of existential concerns

In terms of receiving and accepting information about serious, life-threatening illness and their approaching death, my research participants had very different aptitudes and tools at their disposal to deal with their situation. Some were barely able to talk about it, whereas others—albeit a minority—seemed more prepared and better equipped to encounter what was coming. Although the way in which people take the news about having a terminal condition is very individual, in my material one factor appeared to make a difference: this was the patients' previous exposure to various facets of serious illness, death, and dying. Profiting from previous experience indicates that one *can learn to die*; some of my research patients had more resources than others when it came time to "do" death. That said, my analysis nonetheless demonstrates a general difficulty shared by both the patients and the medical staff in facing the news about the end of life: it proved to be hard to talk and hear about death and dying. There were obstacles in terms of language and communication, and mental imageries and representations relating to death and dying were very limited. One could say that there remained a shortage of cultural models for and of dying. Often, the only language that was readily available in regard to the end of life was that of medicine—yet with medical language it was difficult to talk about sentiments and meanings, that is, the existential aspect of dying.

In the international guidelines for palliative and hospice care, the most commonly reiterated definition explains palliative (or hospice) care as holistic care meeting the patient's physical, psychological, social, and existential (or spiritual) needs (WHO 2019). Of these different aspects of palliative care, in recent years existential (or spiritual) care has been discussed more widely—for instance, in the professional literature—and it has become an object of further research and development in the field (Gijsberts et al. 2019).[216] When investigating what kinds of hopes, wishes, and needs the palliative patients had, I came to a realization about the materiality and embodiedness of existentiality. The existential matters that related to hope and approaching death, for instance, were seldom talked about in a direct manner, but they were nevertheless expressed and addressed in various ways in the discussions. Hence, when Vivian talked at length about the restrictions of her physical condition, or she was remembering some unpleasant encounter with a healthcare practitioner, for instance, those moments often revealed a variety of sentiments, such as fear and anxiety related to her existential condition, which she would not have talked about directly. As Helena described, bodily symptoms had psychological (or spiritual) ramifications which at times caused lots of existential grief, anxiety, and even anger. Existential matters did not exist in isolation from the rest of the patient; living and dying did not divide itself into the categorizations of "physical, psychological, social, and spiritual," but instead the sense of existence, as well as the sense of losing one's existence, was constituted

[216] For instance, the European Association for Palliative Care (EAPC) founded a Spiritual Care Taskforce in 2010, which aims to enhance research on the topic of spiritual care and ameliorate staff competence and confidence in this area (Gijsberts et al. 2019).

by all of these aspects at once. This is what Johnson (2007) refers to when he says that human meaning is embodied; social, emotional, and existential impressions and affects permeate the lived body and become embodied meanings. On a practical level, talking about everyday nuisances, such as a troublesome tummy, was easier than tackling questions about the possible eternity of the soul—even if, in the end, behind both concerns was the anxiety about the coming death.

The existential aspect of care is understood to be integral for palliative care, and thus it is something that ought to be addressed. It follows that the first challenge here is to recognize when a patient is expressing existential anxiety, fear, or feelings of meaninglessness, for instance. Based on my research analysis, I would claim that these issues are not necessarily expressed by means of spiritual, philosophical, or even psychological language; rather, references to embodied relational challenges that patients encounter in their materially mediated everyday life become easily infused with existential worries and concerns. If Heidi's account about her experiences during a colonoscopy, for instance, is reviewed from this ankle, it becomes easier to understand why she was so impacted by it. Her experience not only concerned her hurting body but was about an encounter that affected her whole existence, causing anxiety and a sense of being devastated. Listening to patients' accounts thus granted the recognition that existential anxieties deserve.

Concerning the explicit hopes and wishes of palliative patients, these mostly had to do with hopes for a cure (i.e., not to die) and wishes to live longer and spend more time with one's family (especially children or grandchildren). The most explicitly expressed need was that of being physically cared for at the end of life and at the moment of death; patients needed to be reassured that one could die without pain or having to suffocate to death. However, beneath these very concrete and sensible—although, at times, impossible—wishes (such as the wish not to die) were various kinds of existential sentiments and aspirations that were not necessarily expressed openly but which surfaced in the long discussions, and also became revealed in the ritualized actions that my research patients engaged in.

Rituals at the end of life

Institutional and medical rituals

Based on my research material, I discerned two different types of rituals in which my research participants were involved; one comprised the various institutional rituals and the other the so-called personal rituals. As explained in the beginning of this study, there are various kinds of ritualized practices or actual rituals in various medical settings, be they hospitals, clinics, or hospices. By analyzing medical treatments from the perspective of ritual theories, it became possible to understand what an intimately essential and constitutive element medicine was in the patients' end of life. Following the theoretical insights of Bell, Asad, and Foucault on rituals as forms of embodied learning and adaptation intertwined with issues of power, I have shown how patients align themselves with techno-medical realities of illness. Biomedical treatments,

including actual medications and drugs, and encounters, such as consultations with staff, generated rhythm and structure in the amorphous daily life of a sick patient. As mentioned above, medicine also offered a language to talk about one's situation and a means to picture what was going on. At times, medical treatments came to denote such existential matters such as hope. Treatments and medication could become rituals of and for hope; indeed, for some patients, as long as there was some medical intervention or procedure to look forward to, there remained hope. This was due to the strong trust that patients felt toward biomedical science and specialized cancer care in Finland. In the end, as Bloch claims, rituals are about deference, about "the trust in others that one follows" (Bloch & Kallinen 2017: 88). Through ritualized medical practices, patients not only learned to align their comportment with medicine but also to adapt the medical worldview as a form of metaphysical thinking. Medicine co-constituted patients in multiple manners; it became physically and molecularly part of the patient's body/mind as well as their identity.

Often medicine and biomedical technology functioned as an empowering and enabling element, which granted enhanced agency to the patients and even helped some of their wishes to be fulfilled. For instance, Vivian felt that medicine had given her "extra-time," for which she was ever grateful. At other times, however, biomedical practices disempowered the patient and caused a sense of self-alienation. Medical technologies also challenged the patient's self-identity, revealing things in one's body which one had not previously been aware of. With their "artifactual intentionalities," various types of medical technology, such as imaging technologies, not only revealed things about the body but also constructed it by cumulating information that was otherwise unknown. However, while Sharon (2014: 146) has proposed that the final representation of reality is produced by the technologies themselves (converting the virtual to real), my research material speaks only of situations in which there was always a human subject making interpretations of the representations produced by technologies for the patient. The descriptions, definitions, and interpretations of reality were negotiated and communicated in a multidirectional manner.

Analyzing the effects of medical technologies, be they empowering or disempowering, exposes the interdependent nature of human existence. The relations that the patients had during their illness trajectory, whether with human or non-human elements, were meaningful exactly for this reason; they were part of the patients' embodied realities and co-constituted their actual existence, that is, their living and dying. If we understand agency as an ability to transform the world, as Sax (2006: 474) suggests, then it follows that medicine—seen as ritual, which expresses, practices, and performs agency—has this transformative ability as well. From the perspective of a patient, these transformations were empowering and, at times, disempowering. Some medical practices, or the ways in which they are realized, can end up objectifying patients. According to my research material, possible objectifying practices were overlooked when there was still some hope for a definitive cure, but the practices became more problematic when a

patient knew (or suspected) that their treatments were not about curing but management of a terminal condition. In some cases, encounters with medical staff seemed to color the patient's experience of their end of life, for better or worse.

Day hospice, which became my main actual research site, was also a kind of medical environment. Part of the ritualizations happening in the day hospice related to medical activities, such as consultations with a doctor, but many were built around ordinary, everyday activities, such as eating. Among the terminally ill patients, the small moments of everyday life became precious, almost celebrated, and thus easily ritualized instances, as the shared lunch moments in the day hospice demonstrated. Furthermore, ordinariness and uneventfulness made the space safe for patients whose daily lives had otherwise changed considerably and now included various biomedical procedures.

In a way, the day hospice represented a mixture of Deleuzoguattarian smoothness, exemplified in the open spaces of the hospice home, where patients could wander around, and institutional striations, which were exemplified by structuring rituals. On one hand, it could be argued that by creating striated order and rhythm for the nebulous time of illness full of unknowns, these ritualizations supported and protected the challenged or fragile self-identities of those who were terminally ill. On the other hand, rituals are also practices of power, which did not always serve every patient's interests. In the narratives of my research participants, however, the hospice home represented a safe place to be at the most vulnerable moment of their life. Research participants expressed that the hospice home and the day hospice enabled moments of relief and comfort, and one felt looked after and cared for. Even if the presence of death was less visible in the common conversations than I had expected, it seemed to silently permeate the patients' minds, as Aili pointed out. Yet, it was still possible to talk about death; questions and worries about death and dying were heard and addressed, as happened in Kimmo's long conversation with the night nurse. To conclude, I would say that as a physical place and an ideological concept (spread in media, for instance), hospice permits contemporary Finns to practice thinking about death and dying in addition to the actual practice of dying. It enables a conceptual and discursive alternative for the ubiquitous techno-medical frame of biomedicine. In other words, it constructs *a contemporary model for dying* and offers some adaptable imagery about the end of life, which otherwise seems so absent in contemporary society.

Personal rituals

Medical rituals have been studied rather widely in anthropological research, but the kind of personal rituals and ritualizations that I encountered with my research participants have gained less attention in the studies of death and dying people. Based on my analysis, I have categorized these personal rituals into those which aim to keep death at bay (*death avoidance rituals*) and those which are clearly aimed at preparing for death (*death preparatory rituals*). Some practices had elements of both, but often one could label the activity as one or the other.

Many of the avoidance rituals sought to enhance the body. The dying subject would invent and invite more potentialities with the goal of protecting oneself—or even preventing oneself from dying. The body became the locus of an aesthetic experiment, a ritual site in itself, through which research participants (such as Kimmo with his sports) sought to create new possibilities of life. Complementary and alternative medicine also worked in this manner by creating a virtual ritual space for enhancing life. Furthermore, an alternative healing ritual could also become an attempt to build an alternate ontology, a sort of new ordering of reality, in which the patient was able to regain some control over their situation. Healthy food, sports, and different types of beauty aids were used in order to enhance the powers of the body. All of these personal rituals and ritualizations can be interpreted *as attempts to increase one's own authority and agency* over the situation. In addition, some of these rituals offered the possibility to *apprehend new metaphysical ways of thinking* about oneself and the illness, even if it meant shifting into a new epistemological type of reasoning, such as magic. At times of severe existential crisis, like imminent death, the social pressure to follow the causal scientific orientation becomes practically meaningless. Furthermore, per Giddens, we can see how such activities and practices also functioned as efforts to protect one's self-identity in the face of approaching death and the disintegration which it brings about.

The ritual of writing was very different from rituals concentrating on the body. As seen with Marjo-Riitta, writing in general—and especially writing a blog—was a powerful tool to process one's situation and claim authority. Both reading and writing proved to be very important for those research participants who engaged in them. As Aili stated multiple times, reading was experienced as a salvation and as an essential tool for survival in moments of crisis. Reading and writing could function both as a ritual of avoidance or ritual as preparation. Most often they featured a sort of negotiation about the situation and one's possibilities; one could also learn to adapt and accept their situation by reading and writing about it. For Marjo-Riitta, writing was a way to generate the virtual ritual space in which she could create the kind of deathscape she wished.

Some of the practices I encountered among my research patients were clearly aimed at preparing for one's death and dying. Often the death preparatory rituals were very practical and concerned with this-worldly issues; they were about "tying up loose ends," such as arranging one's economics or re-dividing the responsibilities in the household. Some level of acceptance, or at least recognition of the approaching death, preceded these practices. Since speaking—and, at times, even thinking—about the coming death was difficult, and consequently rare, the moment when it actually happened (for instance, in relation to funeral planning) was exceptional, and thus became easily ritualized. In my research material, funeral planning was this type of preparatory practice, which opened a framed space to encounter one's own mortality and talk about it. Some of the preparatory rituals were empowering for the dying. For instance, the designing and making of a death shirt literally asserted agency in relation to one's death and

the ability to design one's own deathscape. The ritual of death cleaning seemed to function simultaneously as a practical preparation for death as well as a way to organize, go through, and also say goodbye to one's life history. Giving up important material items could also turn out to be a significant moment for the dying, attesting to acknowledgement of the approaching death and even extending one's agency beyond the moment of death.

Religion, nature, and aesthetics as empowering mediations

In addition to various personal rituals and ritualized activities, I encountered other activities reflecting the participatory orientation to the world, which contrasted with the instrumental causality represented by biomedicine. Based on my research analysis, religion and spirituality, nature, and various forms of aesthetics offered powerful tools and practical mediations for patients to orient themselves after a prognosis of terminal illness. Religion and spirituality represent a classic participatory model of relating with the world, which can be in a conflicting relationship with the scientific, causal manner of reasoning and approaching reality that dominates the Western secular societies (Hanegraaff 2003). With most of my research participants, however, their possible religious denominations did not seem to greatly affect their everyday life, not even in the face of death. Most of the religiosity seemed so fluid and flexible that it did not appear to cause any dissonance with the scientific explanation of the world. Instead, many stated that they were not religious, even while admitting "perhaps something more is out there."

Yet, there were a few participants for whom religious questions did matter. Religion functioned as a profound source of support and hope for some patients, such as Siru, whereas for others, like Vivian, it was a disappointment. In addition to the strong affects caused by religion, some research participants, such as Inkeri and Oiva, expressed their spirituality in a very loose and creative manner, mixing spiritual and philosophical understandings of the world with their art.

Rather than relating to religion *per se*, or talking about religious or transcendent matters, my research participants described and talked about deeply affective and special aesthetic moments that were intense enough to cause metaphysical realizations—epiphanies even—in regard to their existential situation. Some had these sorts of special experiences spontaneously by looking at nature scenery, for example, while for others these experiences were induced by specific types of engagement, such as listening to music or reading poetry. Since the experiences varied so much, it took me a while to realize that the common element in all these various special moments was *aesthetics*. For instance, when Heidi saw the hawk eat the blackbird, it made her realize her own mortality and place in the universe. Martti heard a piece of classical music from the car radio, which gave him a vision of Paradise, whereas Aili found fortification of her philosophical understanding of life and death through avid reading. Whether it happened in nature or through the arts, it was the encounter with aesthetics that engendered transformative affective experiences, which brought metaphysical meaning and led to acceptance of such

existential matters as one's approaching death. Hence, I have called these sorts of participatory engagements *aesthetic experiences* with the potentiality to induce metaphysical imagination and meaning-making (Butters 2016).

Aesthetics also functioned as a tool to process memories and tie up one's life, and thus make meaning of the life one had lived. Looking through old photos or at old artwork, or listening to a record collection, like my mother did, are all aesthetic experiences that helped the patients to reach some conclusion. Wherever the element of aesthetics was present, it seemed to work as the mediation through which time, life events, various kinds of emotions and cognitive aspirations were reorganized in a creative, meaningful manner. Here, the human experience was not only ontologically related to the world (Ihde 2009: 23) but also aesthetically so. Based on my analysis, for my research participants it was easier to relate to special moments that engendered metaphysical thinking via the concept of aesthetics rather than religion. In a Western secular society, aesthetics is a culturally more acceptable—and perhaps in some ways more accessible—manner to practice participation and metaphysical thinking (Hanegraaff 2003: 377).

With the help of the Deleuzoguattarian conceptualization of smooth and striated, the analysis showed how both medicine and aesthetics can work as striations creating and promoting patterns of security and rhythm in life and death. Based on my analysis, the difference between these two kinds of striations was that, unlike in the case of medicine, through aesthetics or other kinds of participatory practices my research participants were able to discover and create some metaphysical meaning and find existential consolation in the face of death. Of all of the accounts that I heard from my research participants, the ones involving aesthetics were the most affective and empowering for the patients themselves in regard to their emotional and existential challenges. Whether spontaneous and accidental, or cultivated and sought after, aesthetic experiences enabled metaphysical imagination and meaning-making, which brought great consolation and relief.

The Deleuzoguattarian smoothing through ritual, art, and nature opened up new spaces for hope and change. Such openings can be seen as Kapferer's phantasmagorical space, which invites participants to break free from the constraints or determinations of everyday life by enabling possibilities and potentialities (Kapferer 2006: 673). In other words, these spaces or moments become a form of virtuality, a sort of enhanced facet of actuality. Furthermore, aesthetics and aesthetic experiences transformed relations and enhanced *potentia*. Relations to life, death, and the world were renewed, and this was an empowering experience. Some of the research participants understood their end of life as a kind of final art project. By approaching death in this kind of creative manner, some realized the kind of deathscape for themselves that they wished, and thus they claimed authority over their own death.

11.3 Contributions, limitations, and prospects

Contributions of the study

Since this study combines different approaches to the theme of death and dying, it also contributes to various academic discussions in such fields as death studies and ritual studies, as well as the study of (lived) religion and palliative research.

Within the field of death studies, this research reveals the experiences of the dying people themselves, an important perspective that has been less studied in comparison to the experiences of caregivers or the bereaved. By examining the patients' embodied and embedded experiences not only in relation to the medical context but also in regard to other quotidian elements which comprised their end of life, the work integrates previously often separated research approaches, such as those focusing on questions of (medical) care, on one hand, and those concerning the existential aspects of the dying process, on the other. This kind of integrated approach allows one to see how different aspects of the end of life affect each other and are in a dynamic mutual relationship.

Furthermore, this work joins research done during recent years that emphasizes the relationality of care and dying (Broom and Kirby 2013; Ellis 2013, 2018; van Hout et al. 2015; Håkanson & Öhlén 2016; Vähäkangas & Saarelainen 2019). Akin to sociologist Julie Ellis' (2013) academic focus on the everyday aspect of dying, my research shows how small, quotidian realities and practices form the core experiences of the dying. Studying families with a terminally ill family member, Ellis has noted how "'the big matter of death' was lived through mundane material things and everyday routines" (2013: 261–262). This everyday aspect of the end of life and dying has been somewhat overlooked in the earlier studies, which have often emphasized death and dying either as medical phenomena (Kellehear 2016) or as something spiritually extraordinary with emotional "work to be done," as Ellis puts it (2013: 252). My analysis agrees with and further illuminates Ellis' view on how existentially and spiritually significant aspects (those which Ellis refers to as the assumed "big matter") of dying are interlaced with material, day-to-day realities and experiences. Whereas recent sociological studies have underlined the importance of social relations (with other humans) at the end of life (see, e.g., Broom and Kirby 2013; Håkanson & Öhlén 2016), theologians Auli Vähäkangas and Suvi-Maria Saarelainen (2019) have written about "relational theology," by which they seek to highlight the importance of the patient's personal relations with both human and divine others for maintaining hope. What I have introduced to this conversation is how the relational mediated aspect of human experience shapes the end of life and dying in manifold ways. Some of the mediations, including medicine, have been discussed in earlier studies in the field of medical anthropology (see, e.g., Davis-Floyd 1992; van der Geest 2005; Brody 2010), but my work brings to light other kinds of mediations, such as those of personal rituals and ritualizations, which the earlier research has not discussed.

Studying death rituals as forms of social adaptation or as ways to conquer death and ensure the continuity of life is nothing unusual in anthropology; however, studying death rituals from the perspective of the dying person—as is done in this work—is rare (see Engelke 2019). Thus, this research contributes to the study of death rituals overall. More specifically, the way in which this study has approached death rituals as means of corporeal, emotional, and even metaphysical learning about the end of life and death opens a new perspective on death rituals. The elaboration of both institutional and personal death rituals in this study enriches the understanding of how one can adopt and learn ways of thinking, doing, and being with terminal illness and imminent death via ritual practices. Furthermore, the categorization of death avoidance rituals on one hand and death preparatory rituals on the other elaborates on death rituals in a novel manner.

In terms of the theoretical discussions in the field of the study of religion, this work amplifies the classical discussion on participation (Lévy-Bruhl 1923; Tambiah 1990; Hanegraaff 2003; Luhrmann 2007; Dawes 2014). Here, the participation became manifested especially in the personal rituals of the research patients, many of which involved aesthetics in one form or another. Perhaps this was the most intriguing empirical finding of my work: my research participants related to aesthetics over religion or spirituality when finding solace and metaphysical meaning at the end of life. Although art and religion share common elements, it was fascinating how many of the research participants seemed to separate these two, even purposefully selecting aesthetic elements over religious ones as meaningful and soothing. This could suggest that in comparison to religion and spirituality, aesthetics—like art and nature—is for contemporary Finns a more attractive and malleable way to seek existential meaning. I believe that this is an important question for the study of religion to investigate in more detail in the future.

While there has been interest toward various sorts of alternative healing practices on the borderline of religion and medicine (see McGuire 2008; Rowbottom 2014), there are scant studies of lived religion concerning people with acute, chronic, or life-threatening illnesses, especially from the biomedical frame. The phenomenological first-person perspective of my work is typical, yet the research material is exceptional in the study of lived religion. Subsequently, this work opens new avenues by illuminating the way in which terminally ill patients embodied and lived through their existential challenges in the frame of quotidian life. Exploring the ways in which terminally ill patients negotiate and deal with death and dying in biomedically saturated everyday life increases our understanding of the contemporary intertwinings of medicine, an embodied sense of reality, and metaphysical meaning-making.

This question of the existential aspect of terminal illness brings me to the last facet of the possible contributions of the research findings. As mentioned previously, in palliative research there has been increased interest and a need to understand the existential dimension of palliative care (Gijsberts et al. 2019). However, it still often seems vague what exactly those existential

matters are, how they appear in palliative care, and how they should be taken into consideration in practice (Boston et al. 2011; Gijsberts et al. 2019; Drillaud et al. 2020). Instead of those manifesting in abstract spiritual or religious ideas, practices, or language, my work demonstrates how existential issues arise in and are mediated by various kinds of quotidian settings and embodied situations, and how existential anxieties are frequently entangled with practical and concrete matters. In practice, these anxieties or issues were not always necessarily recognized as "existential," since existential matters are generally considered to comprise something more abstract and transcendent (Drillaud et al. 2020).

The kinds of existential care which proved to be empowering—and thus meaningful—to patients seemed to involve various sorts of relationalities, whether with other human or non-human companions, or with nature and artistic expressions. This finding accords with anthropologist Frédérique Drillaud's recent study from France, which concludes that the existential dimension "appears to reside in the connections between individuals, the relationships and interaction of all those present in the PCU [palliative care unit]" (Drillaud et al. 2020: 12).[217] Our studies find further agreement on the significance of creative, aesthetic, and sensorial activities to enhance the wellbeing of the palliative patients, but also how they represent actual forms of existential or spiritual care. Drillaud et al. (2020) note that given the prominence of the themes of "sensoriality" and "imagination" as existential elements in the field, and the lack of corresponding theoretical data on them, they deserve to be studied further. This is exactly what my study has done. Through theoretization, I have shown how the potentialities and virtualities facilitated by art, ritual, and other forms of aesthetics alleviate existential anxieties and enable patients to practice being with the idea of death and dying, and eventually even practice learning to die. It would be ideal if not just palliative care but also palliative research began considering the existential or spiritual aspects of care in this more nuanced, embodied, and concrete way. This would perhaps lead to new insights within the realm of research and new innovations in regard to actual care.

Critical view of the research process

In qualitative research such as mine, it is not unusual that the actual ethnographic process differs from the original plan to some extent, and even the research questions may be redefined once the reality in the field is revealed. While my research questions remained the same (only becoming more nuanced), the research process did not proceed according to my original plan. I had hoped to do ethnography in various care locations, observing the care staff as well, but this proved to be difficult to arrange, due to ethical reasons such as privacy. In addition, the events in my private life (i.e., my mother's diagnosis and death) altered the course of the ethnography to some extent. Concerning the content of the research, this led the study to focus

[217] Drillaud et al. (2020) studied the expressions of the existential dimension in a palliatice care unit (PCU) in France, but they included only one actual patient in the research; all the other participants were staff members. Thus, although their research material included both observations and interviews, in regard to the patients their analysis was mostly based on observations.

more strictly on the patients' understanding and interpretations of their circumstances. I did converse with the staff at times, but since they were included in the scope of my ethically approved research plan only minimally and I was unable to do proper ethnographic observation of the care situations, their presence in the study is minimal and their approach has been largely omitted from the analysis. In this way, the study ended up concerning the lived reality of the patients more closely than I had initially anticipated. The same phenomenon concerns the relative lack of presence of family members (or significant others) in the research. Since I emphasize the importance of relationality, it would have perhaps made sense to include family members more in the research. This would have broadened the perspectives, but it could have also affected the way in which the patients themselves opened up to me. As explained in the beginning, sometimes meeting a stranger who is an outsider to the family dynamics and not a medical professional can be helpful for patients. It can enable them to express frustrations that they do not wish to air in front of their loved ones. In the end, these shortcomings shaped my study, but in terms of the main focus—that is, understanding the way in which the research participants lived their end of life and experienced their dying—I do not believe that they negatively impacted the final findings.

A major influence on the whole research process was my mother's death only a few months after I had started my ethnography. Time wise, her diagnosis coincided in an unfortunate manner with my fieldwork; as soon as I began forming closer relationships with the research participants, I had to take some time off. In addition to the mere logistics and the time lost in the research, witnessing my mother's illness trajectory and experiencing her death affected me emotionally, of course. Even before her death, I started feeling as if I was suddenly experiencing everything I had been studying about—from the inside. I became sensitized to everything I witnessed, and this could be interpreted as a biased position for a researcher. However, being an insider is a sought-after position in the practice of anthropology; the whole point of anthropological ethnography is to render the researcher as an insider in order to gain a more accurate understanding of the research subject's experiences. Although I could never become an insider in the full sense of the word, since I was not ill or dying, I joined the group of people who mourned and experienced something personal in relation to death and dying. The trick was how to return from the field and from the insider position, to reassume the position of the critical researcher. Thanks to my supervisors, who not only supported me through my hardship but also helped me to sharpen my analytical voice after my personal experiences and immersion in the field, I was able to better differentiate the emic and etic in my research material.

Limitations of the study

The limitations in this study relate to its research methods, analysis, and chosen theories. As explained in the beginning, there were specific reasons why I chose ethnography as the research method. Different methods produce different kinds of data, and as an ethnographic study, this work reflects the reality of a very specific and small group of people. The fact that all of my

research participants were diagnosed with cancer naturally affected the analysis. Most of my research participants were hospice patients, which also makes them a specific type of group of dying individuals in Finland. Most Finns die at a general healthcare center (Forma et al. 2018), and the accessibility of palliative care in Finland varies greatly and is not yet in reach of everyone (Saarto & Finne-Soveri 2019).[218] Consequently, a weakness of the study is that it provides a narrow representation of possible death trajectories. While the prevalence of cancer patients in ethnographic research is a direct reflection of the prevalence of cancer patients in hospices, there is a need to conduct research on other palliative patient groups, such as those suffering from cardiovascular diseases or dementia. Also, there is very little information about the experiences of people who die in other places than hospice. This is an area of study that requires further development in Finland.

Another point that I wish to make in relation to my research method has to do with the theoretization of the research material and the ethnographic reporting. Even if it is reasonable to claim that the ethnographic approach enables the research subjects to have their voice heard, that is only one facet of ethnographic reporting. As pointed out by several anthropologists (see Lutz 2017), writing about research subjects always involves some degree of typifying when the subjects are rendered into exemplars of the research (Lutz 2017: 185). Furthermore, intense theorizing can lead to a kind of depersonalization of the subjects, in which personal contexts can become overlooked or neglected (Beatty 2010, cited in Lutz 2017). This poses a dilemma for every ethnographer: how to write in such a manner that the text is scientifically sound and theoretically insightful, yet simultaneously faithful to the ambiguous nature of reality that escapes categorizations, thus being "true" to the people that it talks about. While I have applied various theoretical conceptualizations to my analysis, I have given space to the descriptions in the field, in which I have sought to unwrap the encounters with my research participants in a conscientious manner. I can only hope that my choices do justice to my research participants and their experiences.

In terms of the methods of analysis, while I followed the general ideas of IPA, I did not apply any software while doing it. I found that my research material was too heterogeneous by its nature, varying from interviews to field notes and field diaries, including also various kinds of texts such as blogs, to be proportionately analyzed in such a mechanical manner. In addition, I found that much of the information that I received from the actual interviews or general encounters with the research participants was gathered by attending to the whole situation, not only the words that were spoken. In addition to the actual uttered words, it was about *how* things were said and *when*, what was *not* said, and other things that were happening at the moment. Here the importance of the research notes and diaries became highlighted. That said, using a software program would have certainly revealed prevalences of some concepts and themes in

[218] An example of another kind of death was written about in *Helsingin Sanomat*, when reporter Katri Kallionpää described her father's dying process without palliative care (Kallionpää 2018a, 2018b).

the interviews; therefore, using a software program for the analysis could have produced an additional layer of information.

In terms of the theoretical conceptualizations, the range of my approaches could be regarded as problematic. One could also ask, for example, how a theory of emotions from the 17th century is still relevant today and, furthermore, how that can be combined with contemporary anthropological ritual theories or with posthuman perspectives, since all of these are associated with their own theoretical discussions and schools of thought. There are a couple of ways to respond to this. First, the different theoretizations operate on different levels of analysis (micro, meso, or meta level), and thus they produce different angles on the topic—which was my intended aim. Some conceptualizations (e.g., such as embodied subjectivity) help us to understand how things are experienced from the first-person perspective, whereas some others (e.g., certain ritual theories) illuminate corporeal experiences from a structural and societal perspective.

Second, there is actually a common ground between all of the approaches that I have applied, which, I believe, allows their combination. The conceptualizations used in this work share in their ontological and epistemological basis; they all highlight the processual and non-dual nature of reality with emphasis on materiality and embodiedness. In addition, they share an understanding of subject as essentially relational and interdependent; there is a certain recognition of the affectivity of the environment and relationships in which we live. This kind of shared general understanding of reality facilitates the application of these particular theoretical views from various and differing intellectual traditions. While I agree that I could have operated with much less theory, the dissertation would not have produced the type of integrated approach to the research topic, which was my intellectual aspiration.

11.4 Conclusion

End of life and dying mediated by medicine, rituals, and aesthetics

This research has produced an analysis of various possible ways to live the end of life and to die in contemporary Finland. A common element found in all the accounts of the research participants was how mediated both living and dying tend to be. The relationship with biomedicine was the most pronounced type that surfaced from the research material; it affected the experience of the end of life in myriad ways. Medical spaces and places, practices and treatments, and biotechnological features were present in every phase of the illness trajectory, including the actual death. Thus, biomedicine was part of everyday life in a most concrete and intimate manner, both physically but also mentally. My research participants referred to themselves as patients, and they talked about themselves and their condition in medical language. But as we have seen, the end of life was also mediated by various participatory practices, such as religion, art, and nature, many of which revolved around interconnectedness.

Overall, a participatory orientation to reality emphasizes relationality and reflects the relational ontology of a human.

My theoretical approach of phenomenology flavored with critical mediated posthumanism brought about analysis of the nuanced ways in which the research participants lived and died via mediations. In the course of the participatory practices that I explored, subjectivity was constituted by multiple affective relations with other beings in various places and spaces. In terms of the relational nature of (especially post)human existence and mediated posthuman corporeality, patients experienced their surroundings in a tangible manner—almost as extensions of their bodies. In line with the theory of mediated posthumanism, which does not see the human being as a fixed, bounded entity separate from the external world but rather as constituted through interrelations with the world, I argue that the significance of one's milieu is even more salient toward the end of life. The lifeworld of a terminally ill patient becomes increasingly dependent on and framed in terms of medicine, various technological supports, and ontological relationality with the environment in general. In sum, the phenomenological approach illuminates the processual nature of living and dying that is affected, experienced, and expressed via multiple mediations, which can be environmental, practice-related, material, social, aesthetic, and so on.

Practical implications and final words

The embodied relationality and the mediated nature of the patients' experiences which this study has illuminated have certain implications for practical care work among palliative patients, and as we have seen, they also evoke ideas for possible further research. First, this study has clearly shown the significance of the environment of palliative and hospice care for the wellbeing of the patients and also those close to them. Since the surroundings affect not only physical and social wellbeing but also emotional and psychological ability to find (existential) meaning or comfort at the end of life, it would be important to pay close attention to spatial and structural matters when planning palliative and hospice care. As described in this work, the space affects the practices; differents spaces support, allow, or perhaps hinder different care practices. In order to create the kind of patient-centered care which is called for today, the planning ought to consider how strongly the space can affect and even produce different types of care.

Second, I would like to highlight the mediated and embodied nature of the existential experiences and emotions, such as fear, grief, or a sense of meaninglessness, but also positive emotions like hope. Based on my analysis, patients could express sentiments of their existential situation by accounting experiences related to their illness trajectories, which often became marked by certain, and at times very strong, emotional memories and affects. These accounts and stories contained significant seeds of anxiety, fear, unresolved suffering, or even trauma, which the patients seemed compelled to recount. Listening to stories and validating emotions about subjective experiences can be an important form of recognizing and addressing a patient's

existential distress. This type of listening could be practiced more systematically in patient care. Further research on how past medical experiences affect and possibly shape a patient's illness and dying trajectory would enhance the knowledge about meaning-making processes at the end of life. Since mediatedness similarly works with positive memories, they could be evoked by small creative activities; this could bring about empowering meanings and a sense of connectedness for the patient—and family members as well.

This relates to my third point. What became very clear to me through my analysis was that the patients reacted to their terminal diagnosis with an almost compulsory need to *do something*. Many research participants commented on how there was "nothing to grasp onto," or that they were "losing their grasp" during the illness trajectory. There was a need to handle the challenging existential situation with something tangible, which could concretize the situation for the patient.[219] When faced with the threat of death, people understandably wanted to ensure that everything possible in terms of medicine was done. At times, however, this need to "do medicine" seemed to continue even after the doctors had told that further biomedical treatments would not ameliorate the prognosis. Persistently continuing with biomedicine in situations where it is medically futile can be seen as an attempt to avoid death. I would also suggest that an underlying motive for this might be the compelling need to simply engage in action and actively be "doing something." It is a way to gain some sense of authority in a situation that otherwise seems completely out of one's control. I see it, therefore, as an attempt to practice agency. In the lack of any other things to do, such as religious rituals which could also bring about the sense of agency, biomedicine can become a ritual to cultivate.

Biomedicine or religious rituals are not, however, the only possible things one might engage in when faced with approaching death. There are a plethora of ways for a patient to enhance their sense of agency and various ritualized manners to bring closure to one's ending life. Palliative care can support and implement some of these concrete things; the embodied involvement in the doing can already augment one's sense of authority. One possible ritual of this kind could be *dignity therapy* (Chochinov et al. 2005; Julião et al. 2017), which has been developed especially for palliative patients in their terminal phases in order to ease their distress and help them find some solace in the face of death.[220] Another, even more concrete example might involve compiling a memorial photo album. Such rituals can function simultaneously as a way to process one's current life situation, remember one's lived life, and create something concrete to leave behind for the bereaved. This kind of ritualized and aesthetic endeavor brings me to my last suggestion.

[219] In Finnish, the verb 'to comprehend' (*käsittää*) is derived from the word 'hand' (*käsi*), suggesting that there is a manner of understanding that happens in a tactile and tangible way.

[220] Dignity therapy is a form of short psychotherapy in which the patient is invited to discuss the issues that matter most for them, or which they would most want remembered as death draws near (Chochinov et al. 2005). The conversations are recorded, transcribed, and edited into a returned final version, which the patient can then bequeath to a friend or family member.

Perhaps the most striking finding that surfaced from my research was the impact that aesthetics had on my research participants. Aesthetics in its various forms—in art, nature, environment, visions, and dreams—brought solace and a sense of connectedness in a way that nothing else could. Moreover, aesthetics was not only a source of comfort but actually engendered metaphysical imagination and meaning-making, thus comprising significant existential support for the patients. The positive effects of art and art therapy are widely recognized in the realm of end-of-life care (e.g., Helin 2011; Lin et al. 2012; Safrai 2013). Art is increasingly used in hospitals; for instance, the palliative and hospice wards at Oulu City Hospital are involved in a cultural project that aims to enhance the use of art for the wellbeing of the patients.[221] It would be important to support these kinds of projects by implementing research that would describe and measure the actual effects that art and aesthetic endeavors in the care space can stimulate in patients.

There is no need to wait for special projects, however, to be able to benefit from aesthetics in palliative and hospice care. Raising awareness about the potentialities of aesthetics to comfort and support patients' existential wellbeing, and enhance the practical understanding of how aesthetics can work as a tool to process and make meaning of one's past life and approaching death, would enable a transformation of the care culture for the benefit of patients. This is especially crucial in an increasingly secular society like Finland, where people can be estranged from religious language and imagery. As a language of art and nature, aesthetics is accessible to everyone.

[221] See https://www.oukapalvelut.fi/kehittamishankkeet/Hankekortti1.asp?ID=778.

RESEARCH MATERIAL

Research diaries

D1 – Diary 1 (pp. 1–139)

D2 – Diary 2 (pp. 1–121)

D3 – Diary 3 (pp. 1–89)

D4 – Diary 4 (pp. 1–34)

The recorded interviews

The interviews are referred to in the text by the first name of the research participant and the interview number (instead of dates).

AILI/ interviews 1-6

HEIDI/ interviews 1-2

HEIKKI/ interviews 1-3

HELENA/ interviews 1-2

INKERI/ interviews 1-4

KIRSI/ interview 1

MARJO-RIITTA/interviews 1-2

MARTTI/ interviews 1-4

MATTI/interview 1-2

OIVA/interviews 1-3

PEKKA/interviews 1-2

SIRU/interviews 1-4

TAINA/interview 1

VIVIAN/interviews 1-3

Written sources by the research participants

A copy of Inkeri's "Since one could even die from it" -artwork

Blogs by the research participants

Sairaan rakas elämä by Heikki Honkala http://sairaanrakaselama.blogspot.com
Syöpä tarinoituu todeksi by Marjo-Riitta Karhunen http://syopatarinoituutodeksi.blogspot.com

All the research material is stored in the Umpio storage space for sensitive data at University of Helsinki.

ANCILLARY MATERIAL

Act on Elderly Service. Laki ikääntyneen väestön toimintakyvyn tukemisesta sekä iäkkäiden sosiaali- ja terveyspalveluista 2012/980.

Current Care Guidelines. 2017. "Kipu." https://www.kaypahoito.fi/hoi50103#s8 (Accessed on 11/23/2019)

Current Care Guidelines. 2019. "Palliatiivinen hoito ja saattohoito." Käypä hoito -suositus. Suomalaisen Lääkäriseuran Duodecimin ja Suomen Palliatiivisen Lääketieteen yhdistyksen asettama työryhmä. Helsinki: Suomalainen Lääkäriseura Duodecim. 2018. http://www.kaypahoito.fi (Accessed on 11/23/2019)

ETENE (National Advisory Board on Social Welfare and Health Care Ethics). 2003. *Saattohoito – Valtakunnallisen terveydenhuollon eettisen neuvottelukunnan muistio.* https://etene.fi/documents/1429646/1559090/Ty%C3%B6ryhm%C3%A4n+raportti+saattohoidosta.pdf/4ca4d3d8-90a7-429e-8ba4-4e1bcfa2d75a (Accessed on 11/23/2019)

ETENE (National Advisory Board on Social Welfare and Health Care Ethics). 2004. *Kuolemaan liittyvät eettiset kysymykset terveydenhuollossa*. https://etene.fi/documents/1429646/1559098/ETENE-julkaisuja+4+Kuolemaan+liittyv%C3%A4t+eettiset+kysymykset+terveydenhuollossa.pdf/6a1cd043-354c-486d-b554-e9f37159924e (Accessed on 5/21/2020)

ETENE (National Advisory Board on Social Welfare and Health Care Ethics). 2012. *Saattohoito Suomessa vuosina 2001, 2009, 2012. Suunnitelmat ja toteutus.* ETENE-julkaisuja 36. Sosiaali- ja terveyministeriö. Helsinki. http://urn.fi/URN:ISBN:978-952-00-3270-8 (Accessed on 5/21/2020)

Hietanen, Päivi. 2015a. "Vuorovaikutus kuolevan potilaan kanssa." Presentation in *Kuolema – suuri mysteeri?* –seminar, Siuntio 6/5/2015. https://www.slideshare.net/laakariliitto/pivi-hietanen-vuorovaikutus-kuolevan-potilaan-kanssa-562015 (Accessed on 5/21/2020)

Hietanen, Päivi. 2016. "Hoitojärjestelmä ei toteuta potilaan parasta." Presentation in *Hyvä kuolema* –seminar at Säätytalo 10/6/2016. https://vimeo.com/album/4173241 (Accessed on 5/21/2020)

Holmberg, Kalle. 2015. "Hyvä kuolema on jokaisen oikeus -saattohoidon seminaari." Seminar on Hospice Care, Finlandia House, Helsinki, 9/24/2015.

HS (*Helsingin Sanomat*). 2019. "Niukka elämä lyö maahan." 1/6/2019. https://www.hs.fi/sunnuntai/art-2000005954997.html (Accessed on 11/23/2019)

HS (*Helsingin Sanomat*). 2014. "Lomautus uhkaa Terhokodin henkilöstöä – 'Syyskuussa teimme 100 000 euroa tappiota.'" September 24, 2014. https://www.hs.fi/kaupunki/art-2000002763971.html (Accessed on 11/23/2019)

Hyvä kuolema on jokaisen oikeus –seminaari. Yhteisvastuu keräyksellä 2014 rahoitettu saattohoitohanke 2015-17. Saattohoidon kehittämisen aloitusseminaari. 9/24/2015. *Good death is everybody's right* inauguratory seminar for a national hospice development project 2015-2017. Finlandia talo, Helsinki.

Kuolema –symposium. *Death*-symposium. Karjalan teologinen seura. 2/15–16/2016. Joensuu.

Mäklin, Suvi & Marjukka Mäkelä. 2008. *Hoitoon pääsy syöpätaudeissa. Kysely sairaanhoitopiireille elokuussa 2008*. Stakes, työpapereita 33/2008.

OKM (Ministry of Education and Culture). 2018. ”Palliatiivisen koulutuksen kehittäminen”-website. https://www.palliatiivisenkoulutuksenkehittaminen.fi/basic-information-of-the-project/ (Accessed on 11/23/2019)

”Samalle portille – Eksistentiaaliset kysymykset saattohoidossa.” *Lääkäripäivät 2018: Ammatillinen koulutustapahtuma lääkäreille.* 1/11/2018 Helsinki.

Saarto, Tiina. 2017. *Palliatiivisen hoidon ja saattohoidon järjestäminen: Työryhmän suositus osaamis- ja laatukriteereistä sosiaali- ja terveydenhuollon palvelujärjestelmälle*. Helsinki: Sosiaali- ja terveysministeriö. https://stm.fi/documents/1271139/5933711/RAPORTTI_Palliatiivisen+hoidon+ja+saattohoidon+j%C3%A4rjest%C3%A4minen.pdf/b3877884-2344-44e4-bc05-f0d12785c1c0 (Accessed on 11/23/2019)

Saarto, Tiina & Harriet Finne-Soveri. 2019. *Suositus palliatiivisen hoidon palveluiden tuottamisesta ja laadun parantamisesta Suomessa: Palliatiivisen hoidon asiantuntijaryhmän loppuraportti*. http://urn.fi/URN:ISBN:978-952-00-4126-7 (Accessed on 11/23/2019)

Saattohoitotutkimuksen päivä –seminaari. *Research in hospice care* – a seminar day. 11/6/2012. Järjestäjinä ETENE, Helsingin yliopiston lääketieteellinen tiedekunta, Societas Gerontologica Fennica ry, Suomen palliatiivisen lääketieteen yhdistys ry ja Suomen palliatiivisen hoidon yhdistys ry. Biomedicum, Helsinki.

STM (Sosiaali- ja terveysministeriö). 2010a. *Hyvä saattohoito Suomessa*. Sosiaali- ja terveysministeriön julkaisuja 2010: 6. http://julkaisut.valtioneuvosto.fi/handle/10024/71949 (Accessed on 10/8/2019)

STM (Sosiaali- ja terveysministeriö). 2010b. *Syövän hoidon kehittäminen vuosina 2010–2020*. Sosiaali- ja terveysministeriön selvityksiä 2010: 6. Helsinki. http://julkaisut.valtioneuvosto.fi/bitstream/handle/10024/72793/selv_2010_6_syovan_hoito_verkko.pdf (Accessed on 10/8/2019)

THL (Terveyden ja hyvinvoinnin laitos). 2016. “Palliatiivisen hoidon järjestäminen.” https://thl.fi/fi/web/ikaantyminen/elaman-loppuvaiheen-hoito/hoidon-jarjestaminen (Accessed on 11/26/2018)

THL (Terveyden ja hyvinvoinnin laitos). 2017. “Kotihoidon asiakasmäärät kasvussa, henkilöstön määrän kasvu ei kaikissa maakunnissa seuraa perässä.” *Tutkimuksesta tiiviisti* 18/2017. Hanna Alastalo, Suvi Vainio & Sari Kehusmaa. http://urn.fi/URN:ISBN:978-952-302-899-9 (Accessed on 11/26/2018)

Training program for hospice educators funded and organized by the Common Responsibility Campaign’s *Good Death* project, once a month during 2016–2017

Valvira (National Supervisory Authority for Health and Welfare). 2018. “Elämän loppuvaiheen hoito.” https://www.valvira.fi/terveydenhuolto/hyva-ammatinharjoittaminen/elaman_loppuvaiheen_hoito (Accessed on 11/23/2019)

YLE1 *Avec Tastula*: “Saavatko pienten lasten äidit kuolla?” Aired 12/12/2014.

YLE1 *Avec Tastula:* “Jälkikirjoitus.” Aired 4/17/2017.

REFERENCES

Aaltonen, Leena. 1992. “Historiallinen katsaus.” In: Kyösti Kiiskinen (ed.), *Hautauskulttuuri Suomessa. Suomen hautaustoimistojen liiton 50-vuotisjuhlakirja.* Jyväskylä: Gummerus.

Aaltonen, Mari, Leena Forma, Pekka Rissanen, Jani Raitanen & Marja Jylhä. 2010. “Transitions in health and social service system at the end of life.” *European Journal of Ageing: Social, Behavioural and Health Perspectives*, 7(2): 91–100.

Aaltonen, Tuula, Sanni Telaranta & Maiju Turunen. 2016. *Esteettisyys hoitotyössä*. Opinnäytetyö AMK. Turun Ammattikorkeakoulu. Hoitotyön koulutusohjelma. Toukokuu 2016/37.

Abrahams, Gareth. 2013. “Introduction.” In: Jean Hillier & Gareth Abrahams (eds), *Deleuze and Guattari: Jean Hillier in Conversation with Gareth Abrahams*. Wroclaw, Poland: Association of European Schools of Planning.

Ampuja, Outi. 2014. “Luonnonrauha – mitä se on ja mistä se löytyy.” In: Outi Ampuja & Miikka Peltomaa (eds), *Huutoja hiljaisuuteen. Ihminen ääniympäristössä*, 275–292. Helsinki: Gaudeamus.

Anhava, Helena. 1983. *Kysy hiljaisuudelta itseäsi*. Helsinki: Otava.

Anttonen, Mirja Sisko. 2016. *Kuoleman vaikeuden lievittäminen kuoleman todellisuuden kohtaavassa ja ohittavassa saattohoidossa: Substantiivinen teoria saattohoidosta potilaan, perheenjäsenen ja hoitohenkilökunnan näkökulmasta.* Tampere University Press.

Anttonen, Veikko. 2010. *Uskontotieteen maastot ja kartat.* Helsinki: Suomalaisen Kirjallisuuden Seura.

Apell, Jedida & Riina Mattila. 2017. *Potilaan kokemus hoitoympäristöstä: Katsaus kirjallisuuteen.* Metropolia Ammattikorkeakoulu, Hoitotyön koulutusohjelma.

Asad, Talal. 1993. *Genealogies of Religion: Discipline and Reasons of Power in Christianity and Islam*. Baltimore: Johns Hopkins University Press.

Atkinson, Paul & David Silverman. 1997. “Kundera’s Immortality: The Interview Society and the Invention of the Self.” *Qualitative Inquiry*, 3(3): 304–25.

Bajc, Vida. 2012. “Abductive Ethnography of Practice in Highly Uncertain Conditions.” *The Annals of the American Academy of Political and Social Science*, 642(1): 72–85. doi:10.1177/0002716212438197

Beatty, Andrew. 2010. “How Did it Feel for You? Emotion, Narrative, and the Limits of Ethnography.” *American Anthropologist* (112)3: 430–43. doi.org/10.1111/j.1548-1433.2010.01250.x

Beccaro, Monica, Massimo Costantini, Paolo Giorgi Rossi, Guido Miccinesi, Maria Grimaldi, Paolo Bruzzi, & ISDOC Study Group. 2006. “Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC).” *Journal of epidemiology and community health*, 60(5): 412–416. doi:10.1136/jech.2005.043646

Becker, Ernest. 1973. *The Denial of Death*. New York: Free Press.

Beebe, Kathryne, Angela Davis & Kathryn Gleadle. 2012. “Introduction: Space, Place and Gendered Identities: Feminist history and the spatial turn.” *Women’s History Review*, 21(4): 523–532. doi:10.1080/09612025.2012.658172

Bell, Catherine. [1992] 2009. *Ritual Theory, Ritual Practice*. New York: Oxford University Press.

Bell, Catherine. [1997] 2009. *Ritual: Perspectives and Dimensions*. New York: Oxford University Press.

Bennett, Michael, Elizabeth Davies & Irene Higginson. 2010. “Review: Delivering research in end-of-life care: problems, pitfalls and future priorities.” *Palliative Medicine*, 24(5): 456–461. doi.org/10.1177/0269216310366064

Bergbom, Ingegerd, Monica Pettersson & Erney Mattsson. 2017. “Patient Clothing–Practical Solution or Means of Imposing Anonymity?” *Journal of Hospital & Medical Management*, 3(3): 22.

Biggerstaff, Deborah & Andrew R. Thompson. 2008. “Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research.” *Qualitative Research in Psychology*, 5(3): 214–224. doi.org/10.1080/14780880802314304

Bleakley, Alan. 2013. “The dislocation of medical dominance: Making space for interprofessional care.” *Journal of Interprofessional Care*, 27(2): 24–30. doi:10.3109/13561820.2013.791672

Bloch, Maurice. 2005. “Ritual and deference”. In: *Essays on Cultural Transmission,* 123–137. New York: Berg.

Bloch, Maurice & Timo Kallinen. 2017. “Interview with Maurice Bloch.” *Suomen Antropologi: Journal of the Finnish Anthropological Society*, 41(4): 87–92. https://journal.fi/suomenantropologi/article/view/63055 (Accessed on 12/1/2020)

Borch, Christian. 2002. “Interview with Edward W. Soja: Thirdspace, Postmetropolis, and Social Theory.” *Distinktion: Journal of Social Theory*, 3(1): 113–120.

Borgstrom, Erica. 2017. “Social Death,” *QJM: An International Journal of Medicine*, 110(1): 5–7. doi.org/10.1093/qjmed/hcw183

Borgstrom, Erica & Julie Ellis. 2017. “Introduction: Researching death, dying and bereavement.” *Mortality*, 22(2): 93–104. doi:10.1080/13576275.2017.1291600

Borgstrom, Erica, Julia Ellis & Kate Woodthorpe. 2019. “‘We Don’t Want to Go and Be Idle Ducks’: Family Practices at the End of Life,” *Sociology*, 53(6): 1127–1142. doi.org/10.1177/0038038519841828

Bosk, Charles. 1980. “Occupational Rituals in Patient Management.” *The New England Journal of Medicine*, 303(2): 71–76. DOI:10.1056/NEJM198007103030203

Boston, Patricia, Anne Bruce & Rita Schreiber. 2011. “Existential Suffering in the Palliative Care Setting: An Integrated Literature Review.” *Journal of Pain and Symptom Management*, 41(3): 604–618. doi.org/10.1016/j.jpainsymman.2010.05.010

Bouchetoux, François. 2014. *Writing Anthropology: A Call for Uninhibited Methods*. New York: Palgrave Macmillan.

Bourdieu, Pierre. 1991. *Language and Symbolic Power*. Cambridge, UK: Polity Press.

Boylorn, Robin M. 2012. "Participants as Co-Researchers." In: Lisa M Given (ed.), *The SAGE Encyclopedia of Qualitative Research Methods* (Vols. 1-0) Thousand Oaks, CA: SAGE Publications. doi.org/10.4135/9781412963909.n31

Braidotti, Rosi. 2006. *Transpositions: On Nomadic Ethics*. Cambridge: Polity Press.

Braidotti, Rosi. 2011. *Nomadic Theory: The Portable Rosi Braidotti*. New York: Columbia University Press.

Braidotti, Rosi. 2013. *The Posthuman.* Cambridge: Polity Press

Braidotti, Rosi. 2019. "A Theoretical Framework for the Critical Posthumanities." *Theory, Culture & Society*, 36(6): 31–61. doi:10.1177/0263276418771486

Bower, Julienne E. 2014. "Cancer-related fatigue—mechanisms, risk factors, and treatments." *Nature Reviews Clinical Oncology*, 11: 597–609. doi.org/10.1038/nrclinonc.2014.127

Brody, Howard. 2010. "Ritual, Medicine, and the Placebo Response." In: William Sax, Johannes Quack & Jan Weinhold (eds), *The Problem of Ritual Efficacy*, 151–167. New York: Oxford University Press.

Broom, Alex. 2015. *Dying: A Social Perspective on the End of Life.* Farnham: Ashgate.

Broom, Alex & Emma Kirby. 2013. "The End of Life and the Family: Hospice Patients' Views On Dying As Relational." *Sociology of Health & Illness*, 35(4): 499–513.

Broom, Alex & John Cavenagh. 2011. "On the meanings and experiences of living and dying in an Australian hospice". *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* 15(1): 96–111.

Butler, Judith. 2004. *Precarious Life: The Powers of Mourning and Violence*. London: Verso.

Butters, Maija. K. 2016. "Aesthetics as metaphysical meaning-making in the face of death," *Approaching Religion*, 6(2): 96–111.

Butters, Maija. K. K. 2017. "Between East and West: A diachronic overview of Finnish death culture." *Death Studies*, 41(1): 51–60.

Campbell, Dave. 2011. "Anthropology's Contribution to Public Health Policy Development." *McGill Journal of Medicine,* 13(1): 76–81.

Carlisle, Clare. 2011. "Spinoza, Part 6: Understanding the Emotions." *The Guardian*. https://www.theguardian.com/commentisfree/belief/2011/mar/14/spinoza-understanding-emotions (Accessed on 5/1/2020)

Carrithers, Michael, Matei Candea, Karen Sykes, Martin Holbraad, and Soumhya Venkatesan. 2010. "Ontology Is Just Another Word for Culture: Motion Tabled at the 2008 Meeting of the Group for Debates in Anthropological Theory, University of Manchester." *Critique of Anthropology*, 30(2): 152–200. doi.org/10.1177/0308275X09364070

Carson, Denise. 2011. *Parting Ways: New Rituals and Celebrations of Life's Passing*. Berkeley: University of California Press.

Casey, Edward S. 2013. *The Fate of Place: A Philosophical History*. Berkeley: University of California Press.

Cassell, Eric J. 2004. *The Nature of Suffering and the Goals of Medicine*. Second edition. New York: Oxford University Press.

Chochinov, Harvey, Max Thomas Hack, Thomas Hassard, Linda J. Kristjanson, Susan McClement, and Mike Harlos, 2005. "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology*, 23(24): 5520–5525.

Christensen, Dorthe Refslund & Kjetil Sandvik. 2014. *Mediating and Remediating Death*. Surrey, UK & Burlington, VT: Ashgate.

Clark, Andy. 2003. *Natural-born Cyborgs: Minds, Technologies, and the Future of Human Intelligence*. Oxford & New York: Oxford University Press.

Clark, David. 2002. "Between hope and acceptance: The medicalisation of dying." *British Journal of Medicine*, 324: 905–907.

Clark, David. 2019. "Controversies in palliative care: a matter of definition." Blog, End of Life Studies, University of Glasgow. http://endoflifestudies.academicblogs.co.uk/controversies-in-palliative-care-a-matter-of-definition/ (Accessed on 12/1/2020)

Clifford, James & George E. Marcus. 1986. *Writing Culture: The Poetics and Politics of Ethnography*. Berkeley: University of California Press.

Clover, Kerrie, Sharon Oultram, Catherine Adams, Laraine Cross, Naomi Findlay & Leah Ponman. 2011. "Disruption to radiation therapy sessions due to anxiety among patients receiving radiation therapy to the head and neck area can be predicted using patient self-report measures." *Psycho-Oncology,* 20: 1334–1341. DOI: 10.1002/pon.1854

Corbin, Juliet & Janice M. Morse. 2003. "The Unstructured Interactive Interview: Issues of Reciprocity and Risks When Dealing with Sensitive Topics." *Qualitative Inquiry*, 9(3): 335–354. doi:10.1177/1077800403009003001

Costanzo, Cari & Verghese Abraham. 2018. "The Physical Examination as Ritual: Social Sciences and Embodiment in the Context of the Physical Examination." *Medical Clinics of North America*, 102(3): 425–431.

Couser, Thomas. 1997. *Recovering Bodies: Illness, Disability, and Life Writing*. University of Wisconsin Press. ProQuest Ebook Central. https://ebookcentral.proquest.com/lib/helsinki-ebooks/detail.action?docID=3444891 (Accessed on 12/1/2020)

Csordas, Thomas J. 1997. *The Sacred Self: A Cultural Phenomenology of Charismatic Healing*. Berkeley: University of California Press.

Csordas, Thomas J. 2011. "Cultural Phenomenology: Embodiment, Agency, Sexual Difference, and Illness." In: Frances E. Mascia-Lees, *A Companion to the Anthropology of the Body and Embodiment*, 137–156. Hoboken, NJ: Wiley. doi:10.1002/9781444340488.ch8

Damásio, António. 2003. *Looking for Spinoza: Joy, Sorrow, and the Feeling Brain*. New York: Harvest/Harcourt, Inc.

Dawes, Gregory W. 2014. "Participation and Causality: Lévy-Bruhl Revisited." *Studies in Religion/Sciences Religieuses*, 43(2): 294–318.

Davies, James. 2010. "Introduction: Emotions in the Field." In: James Davies and Dimitrina Spencer (eds), *Emotions in the Field: The Psychology and Anthropology of Fieldwork Experience*, 1–31. Stanford University Press.

Davies, James and Dimitrina Spencer (eds). 2010. *Emotions in the Field: The Psychology and Anthropology of Fieldwork Experience*. Stanford University Press.

Davies, David. 2015. *Mors Britannica: Lifestyle and Death-style in Britain Today*. Oxford University Press.

Davies, Douglas. 2017. *Death, Ritual and Belief. The Rhetoric of Funerary Rites*. London: Bloomsbury Academic.

Davis-Floyd, Robbie. 1992. *Birth as an American Rite Of Passage*. Berkeley: University Of California Press.

Day, Abby. 2013. "Varieties of Belief over Time: Reflections from a Longitudinal Study of Youth and Belief." *Journal of Contemporary Religion*, 28(2): 277–293. doi:10.1080/13537903.2013.78333

DeGrazia, David. 2017. "The Definition of Death". *The Stanford Encyclopedia of Philosophy*, Spring 2017 Edition). Edited by Edward N. Zalta. https://plato.stanford.edu/archives/spr2017/entries/death-definition (Accessed on 4/10/2020)

Delaunay, Catarina & Alexandre C. Martins. 2015. "Dialectical tensions between caregivers and patients in ART and palliative care: Ethical and moral issues raised by the (bio)medicalization of birth and death." In: Alexandre Cotovio Martins & José Manuel Resende, *The Making of the Common in Social Relations*, 53–100. Newcastle Upon Tyne, UK: Cambridge Scholars Publishing.

Deleuze, Gilles. 2001. *Spinoza: Practical Philosophy*. Translated by Robert Hurley. San Francisco: City Lights Publishers.

Deleuze, Gilles. 2007. "On Spinoza." Lectures by Gilles Deleuze. http://deleuzelectures.blogspot.com/2007/02/on-spinoza.html (Accessed on 12/1/2020)

Deleuze, Gilles & Félix Guattari. 2016. *A Thousand Plateaus: Capitalism and Schizophrenia.* Translation and foreword by Brian Massumi. London: Bloomsbury Academic.

Deleuze, Gilles & Félix Guattari. 1980. *Mille Plateaux.* Paris: Éditions de Minuit.

Dempsey, Laura, Maura Dowling, Philip Larkin & Kathy Murphy. 2016. "Sensitive Interviewing in Qualitative Research." *Research in Nursing & Health*, 39: 480–490.

Desjarlais, Robert. 1992. *Body and Emotion: The Aesthetics of Illness and Healing in the Nepal Himalayas*. Philadelphia: University of Pennsylvania Press.

Desjarlais, Robert. 1994. "The Possibilities of Experience Among the Homeless Mentally Ill." *American Anthropologist* 96(4): 886–901.

Desjarlais, Robert. 1997. *Shelter Blues: Sanity and Selfhood Among the Homeless.* University of Pennsylvania Press.

Desjarlais, Robert. 2016. *Subject to Death: Life and Loss in a Buddhist World*. University of Chicago Press.

Desjarlais, Robert & C. Jason Throop. 2011. "Phenomenological Approaches in Anthropology." *Annual Review of Anthropology*, 40(1): 87–102.

Dewey, John. [1934] 2005. *Art as Experience*. New York: Penguin.

Douglas, Mary. [1966] 2002. *Purity and Danger*. New York: Routledge.

Draper, Jan. 2003. "Blurring, moving and broken boundaries: men's encounters with the pregnant body." *Sociology of Health & Illness*, 25(7): 743–767.

Drillaud, Frédérique, Camille Saussac, Florence Keusch, Danièle Lafaye, Hélène Bely, Véronique Averous, Matthieu Frasca, Patrick Baudry, and Benoît Burucoa. 2020. "The Existential Dimension of Palliative Care: The Mirror Effect of Death on Life." *OMEGA - Journal of Death and Dying*, September 2020. doi.org/10.1177/0030222820952187

Eckhard, Jan. 2018. "Does Poverty Increase the Risk of Social Isolation? Insights Based on Panel Data from Germany." *The Sociological Quarterly*, 59(2): 338–359.

Eklund, Robert. 2008. "Pulmonic ingressive phonation: Diachronic and synchronic characteristics, distribution and function in animal and human sound production and in human speech." *Journal of the International Phonetic Association*, 38(3): 235–324. doi:10.1017/S0025100308003563

Elks, Martha L. 1996. "Rituals and Roles in Medical Practice." *Perspectives in Biology and Medicine*, 39(4): 601–609. doi.org/10.1353/pbm.1996.0030

Ellis, Carolyn & Michael G. Flaherty. 2005. "An Agenda for the Interpretation of Lived Experience". In Ellis & Flaherty (eds), *Investigating Subjectivity: Research on Lived Experience*. Newbury Park: Sage Publications.

Ellis, Julie. 2013. "Thinking beyond rupture: Continuity and relationality in everyday illness and dying experience." *Mortality*, 18(3): 251–269. doi.org/10.1080/13576275.2013.819490

Ellis, Julie. 2018. "Family food practices: relationships, materiality and the everyday at the end of life." *Sociology of Health and Illness*, 40(2): 353–365.

Enfield, Nick J. 2017. "Distribution of Agency." In: N.J. Enfield & Paul Kockelman (eds), *Distributed Agency*, 9–14. New York: Oxford University Press.

Engelke, Matthew. 2019. "The Anthropology of Death Revisited." *Annual Review of Anthropology*, 48(1): 29–44.

Eschenbruch, Nicholas. 2007. *Nursing Stories: Life and Death in a German Hospice.* New York: Berghahn Books.

Eskelinen, Teppo, Hannele Harjunen, Helena Hirvonen & Eeva Jokinen (eds). 2017. *Tehostamistalous*. Jyväskylä: Jyväskylän yliopisto.

Etkind, S.N., A.E. Bone, B. Gomes, N. Lovell, C.J. Evans, I.J. Higginson & F.E. Murtagh. 2017. “How many people will need palliative care in 2040? Past trends, future projections and implications for services.” *BMC Medicine*, 15(102). doi.org/10.1186/s12916-017-0860-2

Feenberg, Andrew. 2006. “Active and Passive Bodies: Don Ihde’s Phenomenology of the Body.” In: Evan Selinger (ed.), *Postphenomenology: A Critical Companion to Ihde*, 189–196. State University of New York Press. ProQuest Ebook.

Fenton Joshua J., Paul R. Duberstein, Richard L. Kravitz, Guibo Xing, Daniel J. Tancredi, Kevin Fiscella, Supriya Mohile, and Rinald M. Epstein. 2018. “Impact of Prognostic Discussions on the Patient-Physician Relationship: Prospective Cohort Study.” *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 36(3): 225–230. DOI: 10.1200/JCO.2017.75.6288

Ferré, Frederick. 1996. *Being and Value: Toward Constructive Postmodern Metaphysics*. Albany: State University of New York Press.

Fingerroos, Outi. 2004. *Haudatut muistot: rituaalisen kuoleman merkitykset Kannaksen muistitiedossa*. Helsinki: Suomalaisen kirjallisuuden seura.

Finlex 27/2004. “Sosiaali- ja terveysministeriön asetus kuoleman toteamisesta”.

Floriani, Ciro & Fermin Schramm. 2012. “Routinization and medicalization of palliative care: Losses, gains and challenges.” *Palliative and Supportive Care*, 10(4): 295–303. doi:10.1017/S1478951511001039

Forma, Leena, Mari Aaltonen, Jutta Pulkki, Jani Raitanen, Pekka Rissanen, Lauri Seinelä, Jaakko Valvanne & Marja Jylhä. 2018. “Pitkäaikaishoito viimeisenä elinvuotena – Vertailussa suuret kaupungit ja muu Suomi 2002–2013.” *Suomen Lääkärilehti*, 8(73): 2086–2091.

Foucault, Michel. 1963. *The Birth of the Clinic*. New York: Pantheon Books.

Foucault, Michel. 1978. *The History of Sexuality*. Translated from the French by Robert Hurley. New York: Pantheon Books.

Foucault, Michel. [1977] 1995. *Discipline and Punish: The Birth of the Prison*. Translated from the French by Alan Sheridan. New York: Vintage Books.

Foucault, Michel.1988. “The Technologies of the Self.” In: Luther H. Martin, Huck Gutman, Patrick H. Hutton (eds), *Technologies of the Self: A Seminar with Michel Foucault,* 16–49. University of Massachusetts Press.

Frank, Arthur W. 1995. *The Wounded Storyteller: Body, Illness and Ethics*. The University of Chicago Press.

Frank, Arthur W. 2000. “The Standpoint of Storyteller.” *Qualitative Health Research*, 10: 354–365. doi:10.1177/104973200129118499

Frank, Arthur W. 2001. “Can We Research Suffering?” *Qualitative Health Research* 1(3): 353–362. doi:10.1177/104973201129119154

Fromm, Erich. 1973. *The Anatomy of Human Destructiveness*. New York: Holt, Rinehart and Winston.

Galushko, Maren, Vanessa Romotzky & Raymond Voltz. 2012. “Challenges in End-of-life Communication.” *Current Opinion in Supportive and Palliative Care*, 6(3): 355–364.

Geertz, Clifford. 1973. *The Interpretation of Cultures*. New York: Basic Books.

Gell, Alfred. 1998. *Art and Agency*. Oxford: Clarendon Press.

Gesler, Wilbert M. 1992. “Therapeutic landscapes: Medical issues in light of the new cultural geography.” *Social Science and Medicine*, 34: 735–746.

Gesler, Wilbert M. 2005. “Therapeutic landscapes: An evolving theme.” *Health and Place*, 11: 295–297.

Gesler, Wilbert M. 2009. “Therapeutic landscapes.” In: Rob Kitchin & Nigel Thrift (eds), *International Encyclopedia of Human Geography*, 229–230. Amsterdam: Elsevier.

Giddens, Anthony. [1991] 2006. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity Press.

Gijsberts, Marie-José, Anke I. Liefbroer, René Otten & Erik Olsman. 2019. “Spiritual Care in Palliative Care: A Systematic Review of the Recent European Literature.” *Medical Science* 7(25).

Given, Lisa M. 2008. “Pseudonym.” *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks, CA: SAGE Publications. doi: 10.4135/9781412963909

Glaser, Barney & Anselm Strauss. 1965. *Awareness of Dying*. Chicago: Aldine.

Goldberg, Daniel.S. 2007. “Religion, the Culture of Biomedicine, and the Tremendum: Towards a Non-Essentialist Analysis of Interconnection.” *Journal of Religion and Health* 46: 99–108. doi.org/10.1007/s10943-006-9080-3

Goodwin-Hawkins, Bryonny, and Andrew Dawson. 2018. “Life’s End: Ethnographic Perspectives.” *Death Studies*, 42(5): 269–74. doi:10.1080/07481187.2017.1396394.

Gordon, Michael. 2015. “Rituals in death and dying: Modern medical technologies enter the fray.” *Rambam Maimonides Medical Journal*, 6(1): e0007. doi:10.5041/RMMJ.10182

Gothóni, Raili & René Gothóni. 2014. “Hiljaisuus uskonnossa – Athosvuoren luostareista retriittien rauhaan.” In: Outi Ampuja & Miikka Peltomaa (eds), *Huutoja hiljaisuuteen. Ihminen ääniympäristössä*, 275–292. Helsinki: Gaudeamus.

Gothóni, Raili. 1987. *Pitkäaikaissairaan vanhuksen maailma ja uskonnollisuus*. Helsinki: Suomalaisen teologisen kirjallisuusseuran julkaisuja 149.

Graham, Elaine. 2004. “Post/Human Conditions”. *Theology & Sexuality*, 10(2): 10–32.

Gramling, Robert, Kevin Fiscella, Guibo Xing et al. 2016. “Determinants of Patient-Oncologist Prognostic Discordance in Advanced Cancer.” *JAMA Oncology*, 2(11): 1421–1426. doi:10.1001/jamaoncol.2016.1861

Grénman, Miia, Ulla Hakala & Barbara Mueller. 2019. “Wellness branding: insights into how American and Finnish consumers use wellness as a means of self-branding.” *Journal of Product & Brand Management*. doi.org/10.1108/JPBM-04-2018-1860

Gysels, Marjolein, Catherine Evans & Irene Higginson. 2012. “Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: A critical interpretive synthesis of the literature.” *BMC Medical Research Methodology*, 12(123). doi.org/10.1186/1471-2288-12-123

Hallamaa, Jaana. 2019. “Etiikan merkitys lääkärin työssä.” https://www.laakariliitto.fi/laakarinetiikka/laakarin-etiikan-filosofiset-perusteet/etiikan-merkitys-laakarin-tyossa/ (Accessed on 12/1/2020)

Hammersley, Martyn. 2006. “Ethnography: Problems and perspectives.” *Ethnography and Education*, 1(1): 3–14.

Hammersley, Martyn & Paul Atkinson, Paul. 2007. *What is ethnography? Ethnography, Principles in Practice*. (3rd ed). New York: Routledge.

Handelman, Don. 2013. “Bruce Kapferer, Deleuzian Virtuality, and the Makings of a Ritual Masterstroke.” In: Bruce Kapferer, Andrew Lattas, Rohan Bastin, and Don Handelman."Portrait: Bruce Kapferer." *Religion and Society*, 4(1): 32–40. https://search-proquest-com.libproxy.helsinki.fi/docview/1768252505?accountid=11365 (Accessed on 10/1/2020)

Hanegraaff, Wouter J. 2003. “How Magic Survived the Disenchantment of the World.” *Religion* 33(4): 357–380.

Haraway, Donna J. 2003. *The Companion Species Manifesto: Dogs, People, and Significant Otherness.* Chicago: Prickly Paradigm Press.

Harjunen, Hannele. 2017. “Terveys, talous ja tehokkaat ruumiit.” In: Teppo Eskelinen, Hannele Harjunen, Helena Hirvonen, Eeva Jokinen Eskelinen, Hannele Harjunen, Helena Hirvonen & Eeva Jokinen (eds), *Tehostamistalous*, 163–180. Jyväskylä: Jyväskylän yliopisto.

Hartig, Terry, Agnes E. van den Berg, Caroline M. Hagerhall, Marek Tomalak, Nicole Bauer, Ralf Hansmann, Ann Ojala, Efi Syngollitou, Giuseppe Carrus, Ann van Herzele, Simon Bell, Marie Camilleri, Therese Podesta & Grete Waaseth. 2011. “Health Benefits of Nature Experience: Psychological, Social and Cultural Processes.” In: Kjell Nilsson et al. (eds), *Forests, Trees and Human Health*, 127–168. New York: Springer.

Harvey, David. 1969. *Explanation in Geography*. London: Edward Arnold.

Harvey, David. 1989. *The Urban Experience*. Baltimore: Johns Hopkins University Press.

Hastrup, Kirsten. 1995. *A Passage to Anthropology: Between Experience and Theory*. New York: Routledge.

Heelas, Paul & Linda Woodhead. 2005. *The Spiritual Revolution: Why Religion is Giving Way to Spirituality*. Malden: Blackwell Publishing.

Heidegger, Martin. [1927] 1962. *Being and Time*. Translated by John Macquarrie & Edward Robinson. New York: Harper and Row.

Helin, Kaija. 2011. *Den vårdande och helande bilden: Möten med bildkonst i vårdandets värld*. Åbo Akademis Förlag – Åbo Akademi University Press.

Helin, Kaija, Martta Holmevaara, Susanna Purola, Riikka Rajala, Anja Rautajoki & Annamari Rivero. 2018. *Kuvataide palliatiivisen hoitotyön välineenä.* Julkaisematon tutkimusraportti, Pirkanmaan hoitokoti, Tampere.

Helin, Kaija. 2018. "Kuvataiteen hoitava ulottuvuus." In: Pauliina Aarva, Hanna Kortejärvi & Kati Sarvela (eds), *Inhimillisyyden vallankumous*, 87-108. Helsinki: Basam Books.

Hellman, Matilda, Marjukka Monni & Anna Alanko. 2017. "Declaring, shepherding, managing: The welfare state ethos in Finnish government programmes, 1950–2015." *Research on Finnish Society*, 10: 9–22.

Henselmans, Inge, Ellen M.A. Smets, Paul K.J. Han et al. 2017. "How long do I have? Observational study on communication about life expectancy with advanced cancer patients." *Patient Education and Counseling*, 100: 1820–1827.

Henselmans, Inge, Hanneke W.M. Van Laarhoven, Jane Van der Vloodt, Hanneke C.J.M. De Haes & Ellen MA Smets. 2017. "Shared decision making about palliative chemotherapy: A qualitative observation of talk about patients' preferences." *Palliative Medicine*, 31(7): 625–633.

Heyland Daren K; Peter Dodek, Graeme Rocker, Dianne Groll, Amiram Gafni, Deb Pichora, sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis & Miu Lam. 2006. "What matters most in end-of-life care: perceptions of seriously ill patients and their family members." *Canadian Medical Association Journal*. 174(5): 627–33. doi: 10.1503/cmaj.050626. PMID: 16505458; PMCID: PMC1389825.

Hietanen, Päivi. 2015b. "Vaikeat vuorovaikutustilanteet." In: Tiina Saarto, Juha Hänninen, Anneli Vainio & Riitta Antikainen (eds). *Palliatiivinen hoito*. Helsinki: Duodecim.

Hildén, Hanna-Mari. 2005. *Making decisions in the face of death: Physicians' and nurses' views of end-of-life decision-making and patient participation*. PhD thesis. Helsinki: University of Helsinki, Faculty of Medicine.

Hinton, John. 1964. "Problems in the care of the dying." *Journal of Chronic Diseases*, 17: 201–205.

Hirvonen, Outi M., Riikka-Leena Leskelä, Lotta Grönholm, Olli Haltia, Antti Rissanen, Kristiina Tyynelä-Korhonen, Eeva K. Rahko, Juho T. Lehto & Tiina Saarto. 2019. "Assessing the utilization of the decision to implement a palliative goal for the treatment of cancer patients during the last year of life at Helsinki University Hospital: a historic cohort study." Acta Oncologica. DOI: 10.1080/0284186X.2019.1659512

Hockey, Jennifer Lorna. 1990. *Experiences of Death: An Anthropological Account*. Edinburgh University Press.

Hockey, Jennifer Lorna, Carol Komaromy & Kate Woodthorpe. 2010. *The Matter of Death: Space, Place and Materiality*. Basingstoke, UK: Palgrave Macmillan.

Hockey, Jenny & Martin Forsey. 2012. "Ethnography is not participant observation: Reflections on the interview." In: Jonathan Skinner (ed.), *The Interview: An Ethnographic Approach*. London: Bloomsbury Academic.

Hofmann, Bjørn & Fredrik Svenaeus. 2018. "How medical technologies shape the experience of illness." *Life Sciences, Society and Policy*, 14(1): 1–11.

Hoffman, Louis & Shawn M. Ellis. 2019. “Ultimate Concern.” In: David A. Leeming (ed.) *Encyclopedia of Psychology and Religion*. Berlin: Springer. doi.org/10.1007/978-3-642-27771-9_200200-1

Holland, Catherine K. 1993. “An ethnographic study of nursing culture as an exploration for determining the existence of a system of ritual.” *Journal of Advanced Nursing*, 18(9): 1461–1470. doi:10.1046/j.1365–2648.1993.18091461

Holmberg, Uno. 1915. *Lappalaisten uskonto.* Porvoo: WSOY.

Holstein, James A. & Jaber F. Gubrium. 1995. “The active interview.” *SAGE Research Methods Online*. doi.org/10.4135/9781412986120

Honko, Lauri, Senni Timonen & Michael Branch. 1993. *The Great Bear. A Thematic Anthology of Oral Poetry in the Finno-Ugrian Languages.* Helsinki: Suomalaisen Kirjallisuuden Seura.

Hoppania, Hanna-Kaisa & Tiina Vaittinen. 2015. “A Household Full of Bodies: Neoliberalism, Care and ‘the Political.’” *Global Society*, 29(1): 70–88. doi:10.1080/13600826.2014.974515

Hoppania, Hanna-Kaisa. 2019. “Politicisation, engagement, depoliticisation – the neoliberal politics of care.” *Critical Social Policy*, 39(2): 229–247.

Horneber, Markus, Gerd Bueschel, Gabriele Dennert, Danuta Less, Erik Ritter & Marcel Zwahlen. 2012. “How Many Cancer Patients Use Complementary and Alternative Medicine: A Systematic Review and Metaanalysis.” *Integrative Cancer Therapies*, 11(3): 187–203. doi:10.1177/1534735411423920

Houtman, Dick and Birgit Meyer (eds). 2012. *Things: Religion and the Question of Materiality*. New York: Fordham University Press.

Hovi, Tuija. 2012. “Clinical services instead of sermons.” *Scripta Instituti Donneriani Aboensis*, 24 : 128–144. doi.org/10.30674/scripta.67413

Howarth, Charles. 2013. “Encountering the ageing body in modernity: fear, vulnerability and “contamination””. *Journal for Cultural Research*, 18(39): 233–248.

Hui, David, Masanori Mori, Henrique A. Parsons, Sun Hyun Kim, Zhijun Li, Shamsha Damani, Eduardo Bruera. 2012. “The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature.” *Journal of Pain and Symptom Management*. 43(3): 582–592.

Hui, David, Zohra Nooruddin, Neha Didwaniya, Rony Dev, Maxine De La Cruz, Sun Hyun Kim, Jung Hye Kwon, Ronald Hutchins, Christiana Liem, & Eduardo Bruera. 2014. “Concepts and Definitions for ‘Actively Dying,’ ‘End of Life,’ ‘Terminally Ill,’ ‘Terminal Care,’ and ‘Transition of Care’: A Systematic Review.” *Journal of Pain and Symptom Management*, 47(1): 77–89.

Husserl, Edmund. [1936] 1954. *The Crisis of European Sciences and Transcendental Phenomenology*. Evanston, IL: Northwestern University Press.

Hutchings, Tim (ed.). 2017. *Materiality and the Study of Religion: The Stuff of the Sacred*. New York: Routledge.

Hutchinson, Sally A., Margaret E. Wilson & Holly S. Wilson. 1994. “Benefits of Participating in Research Interviews.” *Image: The Journal of Nursing Scholarship*, 26: 161–166. doi:10.1111/j.1547-5069.1994.tb00937.x

Håkanson, Cecilia & Joakim Öhlén. 2014. “Connectedness at the End of Life Among People Admitted to Inpatient Palliative Care”. *American Journal of Hospice and Palliative Medicine*, 33(1): 47–54.

Hänninen, Juha. 2001. *Kuolevan kipu ja kärsimys*. Jyväskylä: Duodecim.

Ihde, Don. 2002. *Bodies in Technology*. Minneapolis: University of Minnesota Press.

Ihde, Don. 2009. *Postphenomenology and Technoscience: The Peking University Lectures*. Albany: State University of New York Press.

Ingold, Tim. 2014. “That’s enough about ethnography!” *HAU: Journal of Ethnographic Theory* 4(1): 383–395. doi.org/10.14318/hau4.1.021

Iphofen, Ron. 2013. Research ethics in ethnography/anthropology. Brussels: European Commission. https://ec.europa.eu/research/participants/data/ref/h2020/other/hi/ethics-guide-ethnog-anthrop_en.pdf (Accessed on 5/24/2020)

Irving, Andrew. 2017. *The Art of Life and Death: Radical Aesthetics and Ethnographic Practice.* Chicago: HAU Books.

Itkonen, Juha. 2018. *Kun vauvaonni vaihtuu kuoleman suruun: narratiivinen tutkimus kohtukuolemasta, lapsen kuoleman aiheuttamasta surusta ja selviytymisprosessista sekä kirkon tuesta*. PhD thesis. Helsinki: Helsingin yliopisto.

Jackson, Michael (ed.). 1996. *Things as they are: new directions in phenomenological anthropology*. Bloomington: Indiana University Press.

James, Allison & Jenny Hockey. 2007. *Embodying Health Identities*. New York: Palgrave Macmillan.

Janes, Rita. 2006. “Elämä ilman solunsalpaajahoitoa–totta, tarua vai vallanko valhetta?” *Duodecim*, 122(22): 2725–2732.

Janssens, Rien M.J.P.A. & Guy A.M. Widdershoven. 2012. “An Ethical Enquiry into the Concept of Palliative Care.” In: Christopher Cowley (ed.), *Reconceiving Medical Ethics*, 72–83. London & New York: Continuum.

Jenkins, Richard, Hanne Jessen & Vibeke Steffen. 2005. “Matters of Life and Death.” In: Richard Jenkins, Hanne Jessen & Vibeke Steffen (eds), *Managing Uncertainty. Ethnographic Studies of Illness, Risk and the Struggle for Control*, 9–30.Copenhagen: Museum Tusculanum Press.

Jennings, Theodore. W. 1982. “On Ritual Knowledge.” *Journal of Religion*, 62(2): 111–127.

Johnson, Julia O., Daniel P. Sulmasy & Maria T. Nolan. 2007. “Patients' Experiences of Being a Burden on Family in Terminal Illness.” *Journal of Hospice and Palliative Nursing*, 9(5): 264–269. doi:10.1097/01.NJH.0000289656.91880.f2

Johnson, Mark & George Lakoff. 1999. *Philosophy in the Flesh: The Embodied Mind and Its Challenge to Western Thought*. New York: Basic Books.

Johnson, Mark. 2007. *The Meaning of the Body: Aesthetics of Human Understanding*. The University of Chicago Press.

Julião Miguel, Fatima Oliveira, Baltazar Nunes, António Vaz Carneiro & António Barbosa. 2017. "Effect of dignity therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial." *Palliative & Support Care* 16(6): 628–637.

Julkunen, Raija. 2017. *Muuttuvat hyvinvointivaltiot: Eurooppalaiset hyvinvointivaltiot reformoitavina*. SoPhi. Jyväskylä: University of Jyväskylä.

Kaasa, Stein, Jon H. Loge, Matti Aapro, Tit Albreht, Rebecca Anderson, Eduardo Bruera, Cinzia Brunelli, Augusto Caraceni, Andrés Cervantes, David C. Currow, Luc Deliens, Marie Fallon, Xavier Gómez-Batiste, Kjersti S. Grotmol, Breffni Hannon, Dagny F. Haugen, Irene J. Higginson, Marianne J. Hjermstad, David Hui, Karin Jordan, Geana P. Kurita, Philip J. Larkin, Guido Miccinesi, Friedemann Nauck, Rade Pribakovic, Gary Rodin, Per Sjøgren, Patrick Stone, Camilla Zimmermann & Tonje Lundeby). 2018. "Integration of oncology and palliative care: A Lancet Oncology Commission." *The Lancet Oncology*, 19(11): e588–e653. doi.org/10.1016/S1470-2045(18)30415-7

Kaipainen, Jouni & Olli Rosenqvist. 2013. "Maaseudun hiljaisuuden hyödyntäminen." *Maaseudun uusi aika*. *Maaseutututkimuksen ja -politiikan aikakauslehti*, 21(1): 5–17.

Kallionpää, Katri. 2018a. "'Kuukausia', vastasi hoitaja – seuraavana yönä isäni kuoli, eikä kaikki mennyt niin kuin piti." *Helsingin Sanomat*. 1/21/2018.

Kallionpää, Katri. 2018b. "Ihan tavallinen kuolema." https://www.supla.fi/audio/3148001 (Accessed on 5/25/2019)

Kapferer, Bruce. [1987] 1991. *A Celebration of Demons: Exorcism and the Aesthetics of Healing in Sri Lanka*. Bloomington: Indiana University Press.

Kapferer, Bruce. 2004. "Ritual Dynamics and Virtual Practice: Beyond Representation and Meaning." In: Don Handelman and Galina Lindqvist (eds), *Ritual in Its Own Right: Exploring the Dynamics of Transformation*, 35–54. New York: Berghahn Books.

Kapferer, Bruce. 2006. "Virtuality." In: M. Stausberg, J.A.M. Snoek & J. Kreinath, *Theorizing Rituals: Issues, Topics, Approaches, Concepts*, 671–684 Leiden: Brill.

Kapferer, Bruce. 2010. "Beyond Ritual as Performance. Towards Ritual as Dynamics and Virtuality." *Paragrana*, 19(2): 231–249.

Kapferer, Bruce and Angela Hobart. 2004. "Introduction: The Aesthetics of Symbolic Construction and Experience." In: Angela Hobart & Bruce Kapferer (eds). *Aesthetics in Performance: Formations of Symbolic Construction and Experience*, 1–22. London: Berghahn Books.

Kaptchuk, Ted J. 2011. "Placebo studies and ritual theory: A comparative analysis of Navajo, acupuncture and biomedical healing." *Philosophical Transactions of the Royal Society of London, Series B, Biological Sciences*, 366(1572), 1849–1858. doi:10.1098/rstb.2010.0385

Karhunen, Marjo-Riitta. 2015. "Elämän sietämätön hauraus." In: Timo Purjo (ed.), *Kärsimys ja kuolema elämän tarkoituksen kirkastajina*, 81–116. Viktor Frankl Institute Finland. Tutkimuksia 1. Helsinki: Books on Demand.

Karppinen, Helena. 2019. *Older People's Views Related to Their End of Life: Will-to-live, Wellbeing and Functioning*. Academic dissertation. University of Helsinki, Department of Medicine https://helda.helsinki.fi/bitstream/handle/10138/304409/olderpeo.pdf?sequence=1&isAllowed=y (Accessed on 12/1/2020)

Kristensen, Kasper. 2016. "What Can an Affect Do? Notes on the Spinozist-Deleuzean Account." *LIR.journal*, no 7(16): 11–32.

Katz, Pearl. 1981. "Ritual in the operating room." *Ethnology* 20(4): 335–350.

Kaufman, Sharon R. 2005. *...And a Time to Die. How American Hospitals Shape the End of Life.* New York: Lisa Drew Books/ Scribner.

Kellehear, Allan. 2008. "Dying as a social relationship: a sociological review of debates on the determination of death." *Social Science & Medicine*, 66(7): 1533-44.

Kellehear, Allan. 2014. *The Inner Life of the Dying Person*. New York: Columbia University Press.

Kellehear, Allan. 2016. "The Nature of Contemporary Dying: Obsessions, Distortions, Challenges." *Studies in Christian Ethics*, 29(3): 272–78.

Keller, Mary. 2002. *The Hammer and the Flute: Women, Power, and Spirit Possession*. Baltimore: Johns Hopkins University Press.

Kellogg, Ronald T. 1999. *The Psychology of Writing*. Oxford University Press.

Kimmo Ketola, Maarit Hytönen, Veli-Matti Salminen, Jussi Sohlberg & Leena Sorsa. 2016. *Osallistuva luterilaisuus. Suomen evankelis-luterilainen kirkko vuosina 2012–2015: Tutkimus kirkosta ja suomalaisista.* Kirkon tutkimuskeskuksen julkaisuja 125. Kuopio: Grano.

Ketola, Kimmo, Maarit Hytönen, Veli-Matti Salminen, Jussi Sohlberg & Leena Sorsa. 2018. *Socially Engaged Lutheranism. Finnish attitudes to faith and the Church in the light of surveys and statistics*. The Church Research Institute, Publications 64. https://evl.fi/documents/1327140/40900428/Ktk+-+Socially+Engaged+Lutheranism/9d67d78e-36eb-f0e8-8179-b88ebf6e0159 (Accessed on 12/1/2020)

Kemppainen, Ilona. 2006. *Isänmaan uhrit. Sankarikuolema Suomessa toisen maailmansodan aikana.* Bibliotheca Historica 102. Helsinki: Suomalaisen Kirjallisuuden Seura.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.

Knibbe, Kim & Helena Kupari. 2020. "Theorizing lived religion: introduction." *Journal of Contemporary Religion*, 35(2): 157–176. DOI: 10.1080/13537903.2020.1759897

Knibbe, Kim & Peter Versteeg. 2008. "Assessing Phenomenology in Anthropology: Lessons from the Study of Religion and Experience." *Critique of Anthropology*, 28(1): 47–62. doi:10.1177/0308275X07086557

Knott, Kim. 2010. "Religion, space, and place: The spatial turn in research on religion." *Religion and Society*, 1(1), 29–43. doi.org/10.3167/arrs.2010.010103

Knott, Kim & Myfanwy Franks. 2007. “Secular values and the location of religion: A spatial analysis of an English medical centre.” *Health & Place*, 13(1): 224–237. doi.org/10.1016/j.healthplace.2006.01.001

Koenig, Barbara A., Anthony L. Back & Crawley M. LaVera. 2003. “Qualitative Methods in End-of-Life Research: Recommendations to Enhance the Protection of Human Subjects.” *Journal of Pain and Symptom Management*, 25(4): 43–52. doi.org/10.1016/S0885-3924(03)00060-5

Kong, Lily. 1999. “Cemeteries and columbaria, memorials and mausoleums: narrative and interpretation in the study of deathscapes in geography.” *Australian Geographical Studies*, 37: 1–10.

Korpela, Mari, Laura Hirvi & Sanna Tawah. 2016. “Not alone: Doing fieldwork in the company of family members.” *Suomen Antropologi*, 41(3): 3–20.

Koski, Kaarina. 2011. *Kuoleman voimat: kirkonväki suomalaisessa uskomusperinteessä*. Helsinki: Suomalaisen kirjallisuuden seura.

Kotilainen, Helinä. 2014. ”Tilaa lähtemiselle ja saattohoidolle.” *Suomen Lääkärilehti*, 69(3): 123–124.

Krau, Stephen D. 2016. “The differences between palliative care and end of life care: more than semantics.” *Nursing Clinics of North America*, 51(3): ix-x.

Krawczyk, Marian & Naomi Richards. 2019. “A critical rejoinder to ‘Life’s End: Ethnographic Perspectives’”. *Death Studies*, DOI: 10.1080/07481187.2019.1639903

Krohn, Eino. 1965. *Esteettinen maailma*. Helsinki: Otava

Kubsch, Sylvia, Judy O’Shaughnessy, Jennifer Carrick et al. 2007. “Acceptance of Change in the Healthcare Paradigm: From Reductionism to Holism.” *Holistic Nursing Practice*, 21(3): 140–151. doi:10.1097/01.HNP.0000269151.88602.37

Kübler-Ross, Elisabeth. [1969] 2009. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. London: Routledge.

Kupari, Helena M. 2016. *Lifelong Religion as Habitus: Religious Practice among Displaced Karelian Orthodox Women in Finland*. Numen Book Series; nro 153. Leiden: Brill.

Kvale, Steinar. 1984. “The qualitative research interview.” *Journal of Phenomenological Psychology,* 14(2): 171–196.

Laack, Isabel. 2020. “The New Animism and Its Challenges to the Study of Religion.” *Method & Theory in the Study of Religion*, 32(2): 115–147. doi.org/10.1163/15700682-12341473

Laakkonen, Marja-Liisa. 2005. *Advance care planning: Elderly patients’ preferences and practices in long-term care*. Academic dissertation. University of Helsinki, Department of Medicine, Clinics of Medicine and Geriatrics.

Lamont, Elizabeth B. & Nicholas A. Christakis. 2001. “Prognostic Disclosure to Patients with Cancer near the End of Life.” *Annals of internal medicine*, 134(12): 1096–1105. DOI: 10.7326/0003-4819-134-12-200106190-00009

Large, William. 1996. “On the Meaning of the Word Other in Levinas.” *Journal of the British Society for Phenomenology*, 27(1): 36–52. doi:10.1080/00071773.1996.11007135

Large, William. 2013. “Joy and Sadness.” Lectures on Spinoza. https://www.arasite.org/WLnew/Spinoza/joytosad.html

Latour, Bruno. 2005. *Reassembling the Social: An Introduction to Actor-Network-Theory*. Oxford: Oxford University Press.

Lawrence, Donald P., Bruce Kupelnick, Kimberly Miller, Deirdre Devine & Joseph Lau. 2004. “Evidence Report on the Occurrence, Assessment, and Treatment of Fatigue in Cancer Patients”. *JNCI Monographs*, 32: 40–50. doi.org/10.1093/jncimonographs/lgh027

Lawton, Julia. 1998. “Contemporary hospice care: the sequestration of the unbounded body and ‘dirty dying’.” *Sociology of Health and Illness.* 20(2): 121–143

Lawton Julia. 2000. *The Dying Process: Patinet’s experiences of palliative care.* London: Routledge.

Lawton, M. Powell & Lucille Nahemow. 1973. “Ecology and the aging process”. In C. Eisdorfer & M.P. Lawton (eds) *Psychology of adult development and aging*. Washington D.C.: American Psychological Association.

LeBuffe, Michael. 2015. “Spinoza's Psychological Theory.” In: Edward N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy* (Spring 2015 Edition). https://plato.stanford.edu/archives/spr2015/entries/spinoza-psychological

Leder, Drew. 1992. “A Tale of Two Bodies: The Cartesian Corpse and the Lived Body.” In: Drew Leder (ed.), *The Body in Medical Thought and Practice* (Philosophy and Medicine, Vol. 43), 17–35. Dordrecht: Springer.

Lefebvre, Henri. 1974. *La production de l’espace*. Paris: Anthropos.

Lehto, Juha. 2015. “Hoitolinjauksen teko ja sen merkitys.” In: Tiina Saarto, Juha Hänninen, Anneli Vainio & Riitta Antikainen (eds), *Palliatiivinen hoito*. Helsinki: Duodecim Kustannus.

Lehto, Juha, Elisa Marjamäki & Tiina Saarto. 2019. “Elämän loppuvaiheen ennakoiva hoitosuunnitelma.” *Lääketieteellinen Aikakauskirja Duodecim*, 135(4): 335–342.

Leming, Michael R. 2003. “The History of the Hospice Approach.” In: Clifton D. Bryant (ed.) *Handbook of Death and Dying*, pp. 485–495. London: Sage Publications.

Lerer, Lilly. 2015. “Slowing Down Medicine: The Plural Worlds of Hospice.” *Anthropology & Aging*, 36(1): 45–61. doi:10.5195/aa.2015.64

Lewis, Milton J. [2006] 2011. *Medicine and Care of the Dying: A Modern History*. New York: Oxford University Press / Oxford Scholarship Online. doi:10.1093/acprof:oso/9780195175486.001.0001

Lévy-Bruhl, Lucien. 1923. *Primitive Mentality*. Translated by L.A. Clare. Oxford: Macmillan.

Lévy-Bruhl, Lucien. 1949. *Les carnets de Lucien Lévy-Bruhl*. Paris: Presses universitaires de France.

Lin, Ming-Hwai; Shwu-Lan Moh, Yu-Cheng Kuo, Pin-Yuan Wu, Chiung-Ling Lin, Mei-Hui Tsai, Tzeng-Ji Chen and Shinn-Jang Hwang. 2012. “Art therapy for terminal cancer patients in a hospice palliative care unit in Taiwan.” *Palliative and Supportive Care*, 10(1): 51–57. doi:10.1017/S1478951511000587

Lloyd, Genevieve. 1996. *Routledge Philosophy GuideBook to Spinoza and the Ethics*, Taylor & Francis Group. ProQuest Ebook Central, https://ebookcentral-proquest-com.libproxy.helsinki.fi/lib/helsinki-ebooks/detail.action?docID=170059.

Luhrmann, Tanya M. 1991. *Persuasions of the witch's craft: Ritual magic in contemporary England*. Harvard University Press.

Luhrmann, Tanya .M. 2007. “How do you learn to know that it is God who speaks?” In: David Berliner & Ramon Sarró (eds) *Learning Religion: Anthropological Approaches*, 83–102. Berghahn Books. http://www.jstor.org/stable/j.ctt9qcmz4.9. (Accessed on 12/1/2020)

Lutz, Catherine. 2017. “What Matters?” *Cultural Anthropology*, 32(2): 181–191. doi:10.14506/ca32.2.02

Lyratzopoulos, Georgios; Jane Wardle & Greg Rubin. 2014. “Rethinking diagnostic delay in cancer: how difficult is the diagnosis?” *British Medical Journal*, 349: g7400.

Lysen, Flora & Patricia Pisters. 2012. “Introduction: The Smooth and the Striated.” *Deleuze Studies*, 6(1): 1–5. doi.org/10.3366/dls.2012.0042

Lämsä, Riikka. 2008. “Sairaalan tutkimiseen on vaikea saada lupaa.” *Suomen lääkärilehti*, 63(22): 2080–2082.

Lämsä, Riikka. 2016. “Kokemuksia ja metodologisia pohdintoja etnografiasta: Puheenvuoro.” *Sosiaalilääketieteellinen aikakauslehti*, 53(3): 211–214.

Lämsä, Riikka. 2013. *Potilaskertomus - Etnografia potiluudesta sairaalaosaston käytännöissä*. Tutkimus 99. Terveyden ja hyvinvoinnin laitos. Tampere.

Lääkäriliitto. 2019. https://www.laakariliitto.fi/liitto/etiikka/laakarinvala/ (Accessed on 12/1/2020)

Lääkäriliitto. 2019b. *Luottamus: väestökysely.* https://www.laakariliitto.fi/site/assets/files/5227/luottamus_kooste_nettiin_2.pdf (Accessed on 12/1/2020)

Lääkärin etiikka. 2013. (7. painos) Suomen Lääkäriliitto. Chief Editor: Samuli Saarni. https://www.laakariliitto.fi/site/assets/files/5164/laakarin_etiikka_2013.pdf (Accessed on 12/1/2020)

Magnusson, Margareta. 2017. *Döstädning: Ingen sorglig historia*. Stockholm: Albert Bonniers.

Magnusson, Margareta. 2018. *The Gentle Art of Swedish Death Cleaning: How to Free Yourself and Your Family from a Lifetime of Clutter*. New York: Simon and Schuster.

Mahmood Saba. 2001. “Rehearsed Spontaneity and the Conventionality of Ritual: Disciplines of ‘Ṣalāt,’” *American Ethnologist*, 28(4): 827–853. https://www.jstor.org/stable/3094937 (Accessed on 3/17/2019)

Mahmood, Saba. 2005. *Politics of Piety: The Islamic Revival and the Feminist Subject*. Princeton: Princeton University Press.

Marshall, David. 2005. "Food as ritual, routine or convention." Consumption Markets & Culture, 8(1): 69–85. doi:10.1080/10253860500069042

Massumi, Brian. 2002. *Parables for the virtual: Movement, Affect, Sensation.* Durham: Duke University Press.

Matthews, Tamyra; Donald Baken, Kirsty Ross, Emily Ogilvie & Lizzy Kent. 2019. "The experiences of patients and their family members when receiving bad news about cancer: A qualitative meta-synthesis." *Psycho-Oncology*. 28: 2286– 2294. doi.org/10.1002/pon.5241

McCartney James J. & Jane Mary Trau. 1990. "Cessation of the artificial delivery of food and fluids: defining terminal illness and care." *Death Studies*. 14(5):435–444.

McGuire, Meredith B. 2008. *Lived Religion. Faith and Practice in Everyday Life.* Oxford University Press.

McInerney, Fran. 1992. "Provision of food and fluids in terminal care: A sociological analysis." *Social Science & Medicine*, 34(11): 1271–1276.

McNamara, Beverley. 2004. "Good enough death: autonomy and choice in Australian palliative care," *Social Science & Medicine,* 58(5): 929–938.

Menzfeld, Mira. 2017. *Anthropology of Dying: A Participant Observation with Dying Persons in Germany*. Springer.

Merleau-Ponty, Maurice. [1945] 2005. *Phenomenology of Perception*. Taylor and Francis E-Library. doi.org/10.4324/9780203994610

Merriam-Webster. 2020. "Technology." Merriam-Webster.com Dictionary, https://www.merriam-webster.com/dictionary/technology (Accessed on 12/1/2018)

Metcalf, Peter & Richard Huntington. 1991. *Celebrations of Death: The Anthropology of Mortuary Ritual*, Second edition. Cambridge University Press.

Miettinen, Terhikki T. 2001. *Palliative Care through Relatives' Eyes*. Doctoral dissertation. Tampere: University of Tampere.

Mintz, Sidney W. & Christine M. Du Bois. 2002. "The Anthropology of Food and Eating." *Annual Review of Anthropology*, 31(1): 99–119.

Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. New York: Routledge.

Molander, Gustaf. 1999. *Askel lyhenee, maa kutsuu–yli 80-vuotiaiden kuolema eletyn elämän valossa.* Helsinki: Suomen Mielenterveysseura, Kuntoutuksen edistämiskeskus.

Molassiotis, A., P. Fernadez-Ortega, D. Pud, G. Ozden; J.A. Scott, V. Panteli, A. Margulies, M. Browall, M. Magri, S. Selvekerova, E. Madsen, L. Milovics, I. Bruyns, G. Gudmundsdottir, S. Hummerston, A.M.A. Ahmad, N. Platin, N. Kearney & E. Patiraki. 2005. "Use of Complementary and Alternative Medicine in Cancer Patients: A European Survey." *Annals of Oncology*, 16(4): 655–663.

Moore, Andrew, Bernie Carter, Anne Hunt and Kay Sheikh. 2013. "'I am closer to this place'—Space, place and notions of home in lived experiences of hospice daycare." *Health & Place*, 19(1): 151–158.

Moreman, Christopher M. 2014. "On the Relationship between Birds and Spirits of the Dead." *Society and Animals*, 22(5): 481–502.

Morris, Sara M. & Carol Thomas [2007] 2016. "Placing the Dying Body: Emotional, Situational and Embodied Factors in Preferences for Place of Final Care and Death in Cancer." In: Liz Bondi & Joyce Davidson (eds), *Emotional Geographies*, 19–31. New York: Routledge.

Moser, Torsten, Menna Creed, Robyn Walker, and Gernot Meier. 2020. "Radiotherapy tattoos: Women's skin as a carrier of personal memory—What do we cause by tattooing our patients?" *The Breast Journal*, 26(2): 316–318. doi:10.1111/tbj.13591

Mostafazadeh-Bora, Mostafa & Amin Zarghami. 2017. "Breaking and Sharing Bad News in End of Life: The Religious and Culture Matters." *Journal of Religion and Health* 56: 1655–1657. doi.org/10.1007/s10943-016-0249-0

Mroueh, R., A. Haapaniemi, T. Saarto, L. Grönholm, R. Grénman, T. Salo & A.A. Mäkitie. 2019. "Non-curative treatment of patients with oral tongue squamous-cell carcinoma." *European Archives of Oto-rhino-laryngology*, 276(7): 2039–2045. doi:10.1007/s00405-019-05456-y

Mullaney, Tara, Kristina Olausson, Lena Sharp, Björn Zackrisson, David Edvardsson & Tufve Nyholm. 2016. "The influence of a department's psychosocial climate and treatment environment on cancer patients' anxiety during radiotherapy." *European Journal of Oncology Nursing*, 20: 113– 118. doi:10.1016/j.ejon.2015.06.009

Mullaney, Tara, Helena Pettersson, Tufve Nyholm, & Erik Stolterman. 2012. "Thinking beyond the Cure: A Case for Human-Centered Design in Cancer Care." *International Journal of Design* [Online] 6:3. Available: http://blog.ijdesign.org/index.php/IJDesign/article/view/1076 (Accessed on 1/8/2020)

Mäenpää, Hanna O. 2010. "Glioома kuriin – Aikuisten gliooman hoito on monivaiheista." *Duodecim*, 126(14): 1669–1675.

Nilsson, Kjell, Marcus Sangster, Christos Gallis, Terry Hartig, Sjerp de Vries, Klaus Seeland & Jasper Schipperijn (eds). 2011. *Forests, Trees and Human Health*. New York: Springer.

Nirkko, Juha & Kari Mikko Vesala (eds). 2004. *Kirjoituksia maan sydämeltä – tutkimusnäkökulmia maanviljelijöiden kilpakeruuaineistoon*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Nissinen, Anna-Kaisa, Sanna Karjalainen & Sirpa Tölli. 2019. *Palliatiivinen sedaatio aiheuttaa moraalista ahdistusta sairaanhoitajille*. ePooki. Oulun ammattikorkeakoulun tutkimus- ja kehitystyön julkaisut 4. http://urn.fi/urn:nbn:fi-fe201902013796 (Accessed on 1/8/2020)

Noyes, Russell, Jr. & John Clancy. 1977. "The dying role: Its relevance to improved patient care." *Psychiatry*, 40(1): 41–47.

Närvä, Jaakko. 2020. “Kysymys uskonnon määrittelystä.” In: Heikki Pesonen & Tuula Sakaranaho (eds), *Uskontotieteen ilmiöitä ja näkökulmia*, 55–70. Helsinki: Gaudeamus.

OECD & WHO. 2017. *State of Health in the EU: Finland Country Health Profile 2017.* http://www.euro.who.int/__data/assets/pdf_file/0011/355979/Health-Profile-Finland-Eng.pdf?ua=1 (Accessed on 1/8/2020)

Oksala, Johanna. 2013. “Feminism and Neoliberal Governmentality.” *Foucault Studies*, 0(16): 32–53. doi.org/10.22439/fs.v0i16.4116

Olsen, Molly L., Keith M. Swetz, & Paul S. Mueller. 2010. “Ethical decision making with end-of-life care: Palliative sedation and withholding or withdrawing life-sustaining treatments.” *Mayo Clinic Proceedings*, 85(10): 949–954. doi:10.4065/mcp.2010.0201

Olson, Kay / Blue. 2007. “Making Connections: Linkages Through Disability Blogging.” *Disability Studies Quarterly*, 27(1/2). doi.org/10.18061/dsq.v27i1/2.6

OncoLink Team. 2020. *Pictorial Overview of the Radiation Therapy Treatment Process*. https://www.oncolink.org/print/pdf/2092?print_2092.pdf (Accessed on 9/1/2020)

Orell-Kotikangas, Helena. 2015. “Ravitsemustila ja sen arviointi.” In: Tiina Saarto, Juha Hänninen, Anneli Vainio & Riitta Antikainen (eds), *Palliatiivinen hoito*. Helsinki: Duodecim.

Orsi, Robert.1985. *The Madonna of 115th Street: faith and community in Italian Harlem, 1880-1950*. Yale University Press

Osborne, Thomas & Nikolas Rose. 2004. “Spatial Phenomenotechnics: Making Space with Charles Booth and Patrick Geddes.” *Environment and Planning D: Society and Space*, 22(2): 209–228. doi.org/10.1068/d325t

Paasonen, Susanna. 2017. ”Affekti suhteina ja intensiteettinä.” *Tieteessä Tapahtuu*, 35(2). https://journal.fi/tt/article/view/62067 (Accessed on 1/8/2020)

Pajari, Ilona, Jussi Jalonen, Riikka Miettinen & Kirsi Kanerva (eds). 2019. *Suomalaisen kuoleman historia*. Helsinki: Gaudeamus.

Parker-Oliver, Debra. 2000. “The Social Construction of the ‘Dying Role’ and the Hospice Drama.” *OMEGA - Journal of Death and Dying*. 40(4): 493–512. doi:10.2190/YT9D-12Y2-54LY-TCMN.

Parsons, Talcott. 1991. *The Social System*. With a New Preface by Bryan S. Turner. New York: Routledge.

Pastrana, Tania, Saskia Jünger, Cristoph Ostgathe, Frank Elsner, & Lukas Radbruch. 2008. “A matter of definition – key elements identified in a discourse analysis of definitions of palliative care.” *Palliative Medicine*, 22(3): 222–232. doi.org/10.1177/0269216308089803

Paulsen, O., P. Klepstad, J. Rosland et al. 2014. “Efficacy of methylprednisolone on pain, fatigue, and appetite loss in patients with advanced cancer using opioids: A randomised, placebo-controlled, double-blind trial.” *Journal of Clinical Oncology*, 32: 3221–3228.

Pentikäinen, Juha. 1968. *The Nordic Dead-child Tradition: Nordic Dead-child Beings: A Study in Comparative Religion*. Translated by Antony Landon. Helsinki: Suomalainen tiedeakatemia - Academia scientiarum Fennica 1968.

Pentikäinen, Juha. 1990. *Suomalaisen lähtö - Kirjoituksia pohjoisesta kuolemankulttuurista*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Perkins, Harvey C. & David C. Thorns. 2011. *Place, Identity and Everyday Life in a Globalizing World*. London: Red Globe Press.

Peräkylä, Anssi. 1988. "Four Frames of Death in Modern Hospital." In: Anne Gilmore & Stan Gilmore (eds), *A Safer Death*, 51–59. New York: Plenum Press.

Peräkylä, Anssi. 1989. "Appealing to the 'Experience' of the Patient in the Care of the Dying." *Sociology of Health and Illness*, 11(2): 117–134.

Peräkylä, Anssi. 1990. *Kuoleman monet kasvot: Identiteettien tuottaminen kuolevan potilaan hoidossa*. Tampere: Vastapaino.

Pessin, Hayley; Michele Galietta, Christian J. Nelson, Robert Brescia, Barry Rosenfeld & William Breitbart. 2008. "Burden and benefit of psychosocial research at the end of life." *Journal of Palliative Medicine*, 11(4): 627–632. doi:10.1089/jpm.2007.9923

Philpin, Susan M. 2002. "Rituals and nursing: a critical commentary." *Journal of Advanced Nursing*, 38(2): 144–151.

Pietarinen, Juhani. 1993. *Ilon filosofia - Spinozan käsitys aktiivisesta ihmisestä*. Helsinki: Yliopistopaino.

Piili, Reetta. 2019. *End-of-Life Decision-Making in Cancer Patients: Attitudes, ethics and background factors among Finnish physicians and medical students*. Doctoral dissertation. University of Tampere, Doctoral Programme in Medicine and Life Sciences.

Pink, Sarah. 2015. *Doing Sensory Ethnography*. Second Edition. Los Angeles: SAGE.

Pohjanheimo, Outi. 2018. *Etsiä, hoivata, leikkiä. Maagisen ajattelun rikastuminen; intuitiivinen ajattelu ja emootiot parantamiseen liittyvässä etnografisessa aineistossa.* Doctoral Thesis. University of Helsinki.

Pohjolainen, Tiiu. 2019. "Comforting hospital walls." *Aalto University Magazine*, 2019: 24.

Probst, Sebastian, Anne Arber & Sara Faithfull. 2013. "Malignant fungating wounds – The meaning of living in an unbounded body." *European Journal of Oncology Nursing*, 17(1): 38–45.

Ptacek JT, Eberhardt TL. 1996. "Breaking bad news: a review of the literature." *Journal of the American Medical Association*. 276(6): 496–502.

Quartier, Thomas. 2010. "Deathbed rituals: Roles of spiritual caregivers in Dutch hospitals." *Mortality*, 15(2): 107–121. doi:10.1080/13576275.2010.482769

Raivo, Petri. 2007. "Unohdettu ja muistettu suomalainen Karjala." In: Outi Fingerroos, Jaana Loipponen & Kari Alenius (eds), *Nykytulkintojen Karjala*, 55–74. Helsinki: SKS.

Ram, Kalpana & Christopher Houston. 2015. "Introduction: Phenomenology's Methodological Invitation." In: Kalpana Ram & Christopher Houston (eds), *Phenomenology in Anthropology: A Sense of Perspective*, 1–25. Indiana University Press. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/helsinki-ebooks/detail.action?docID=2120281

Randall, Fiona & Robert S. Downie. 1999. *Palliative Care Ethics: A Companion for All Specialities* (2nd edition). Oxford University Press.

Randall, Fiona & Robert S. Downie. 2006. *The Philosophy of Palliative Care: Critique and Reconstruction*. Oxford University Press.

Raposa, Michael L. 2004. "Ritual Inquiry." In: Kevin Schilbrack (ed.), *Thinking through Rituals: Philosophical Perspectives*, 113–127. New York: Routledge.

Rashid, Marghalara, Vera Caine & Helly Goez. 2015. "The Encounters and Challenges of Ethnography as a Methodology in Health Research." *International Journal of Qualitative Methods* 14(5). doi.org/10.1177%2F1609406915621421

Rautakorpi, Liisa K., Johanna M. Mäkelä, Fatemeh Seyednasrollah, Anna M. Hammais, Tarja Laitinen, Outi M. Hirvonen, Heikki Minn, Laura L. Elo & Sirkku M. Jyrkkiö. 2017. "Assessing the utilization of radiotherapy near end of life at a Finnish University Hospital: A retrospective cohort study." *Acta Oncologica*, 56(10): 1265–1271. doi:10.1080/0284186X.2017.1324638

Rautakorpi, Liisa K., Fatemeh Seyednasrollah, Johanna M. Mäkelä, Outi M. Hirvonen, Tarja Laitinen, Laura L. Elo & Sirkku M. Jyrkkiö. 2017. "End-of-life chemotherapy use at a Finnish university hospital: A retrospective cohort study." *Acta Oncologica*, 56(10): 1272–1276. doi:10.1080/0284186X.2017.1332424

Recuber, Timothy. 2017. "Digital afterlives: Learning from blogs of the terminally ill." *Discover Society*. https://discoversociety.org/2017/01/03/digital-afterlives-learning-from-blogs-of-the-terminally-ill/ (Accessed on 11/1/2020)

Reeves, Scott, Ayelet Kuper & Brian David Hodges. 2008. "Qualitative Research Methodologies: Ethnography." *British Medical Journal* 337(7668): np.

Ressler, Pamela K, Ylisabyth S. Bradshaw, Lisa Gualtieri, Kenneth Kwan Ho Chui. 2012. "Communicating the Experience of Chronic Pain and Illness Through Blogging." *Journal of Medical Internet Research*, 14(5): e143. DOI: 10.2196/jmir.2002

Reuter, Martina. 1999. "Merleau-Ponty's Notion of Pre-Reflective Intentionality." *Synthese*, 118(1): 69–88.

Reynolds, Lisa M., Ian P. Bissett & Nathan S Consedine. 2018. "Emotional predictors of bowel screening: the avoidance-promoting role of fear, embarrassment, and disgust." *BMC Cancer*, 18(1): 518. doi:10.1186/s12885-018-4423-5

Rier, David. 2000. "The missing voice of the critically ill: a medical sociologist's first-person account." *Sociology of Health & Illness*, 22(1): 68–93. doi:10.1111/1467-9566.00192

Risse, Guenter B. 2014. "From admission to discharge: The hospital as house of rituals." Lecture, New York Academy of Medicine, September 27, 2000. https://www.academia.edu/9551529/From_Admission_to_Discharge_The_Hospital_as_House_of_Rituals (Accessed on 10/1/2018)

Robinson, Jackie, Merrin Gott, Clare Gardiner & Christine Ingleton. 2017. "Specialist palliative care nursing and the philosophy of palliative care: A critical discussion." *International Journal of Palliative Nursing*, 23(7): 352–358.

Robinson, Jeffrey D. & Reshma Jagsi. 2016. “Physician-Patient Communication—An Actionable Target for Reducing Overly Aggressive Care Near the End of Life.” *JAMA Oncology*, 2(11): 1407–1408. doi:10.1001/jamaoncol.2016.1948

Rogers, Kara. 2018. “Biophilia hypothesis.” *Encyclopædia Britannica*. https://www.britannica.com/science/biophilia-hypothesis (Accessed on 10/1/2018)

Rokkonen, Lilli & Iiris Lehto. 2017. “Tehokasta itsehoivaa.” In: Teppo Eskelinen, Hannele Harjunen, Helena Hirvonen, Eeva Jokinen Eskelinen, Hannele Harjunen, Helena Hirvonen & Eeva Jokinen (eds), *Tehostamistalous*, 181–202. Jyväskylä: Jyväskylän yliopisto.

Rowbottom, Anne. 2014. “Chronic Illness and the Negotiation of Vernacular Religious Belief.” In: Marion Bowman and Ulo Valk (eds), *Vernacular Religion in Everyday Life : Expressions of Belief.* London: Routledge.

Saarelainen, Suvi-Maria. 2017. *Meaningful life with(out) cancer: Coping narratives of emerging Finnish adults*. Doctoral dissertation. University of Helsinki, Faculty of Theology.

Saarikangas, Kirsi. 2006. *Eletyt tilat ja sukupuoli*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Saarto, Tiina. 2015. ”Syövän hoitolinjat.” In: Tiina Saarto, Juha Hänninen, Anneli Vainio & Riitta Antikainen (eds). *Palliatiivinen hoito*. Helsinki: Duodecim.

Saarto, Tiina. 2020. Professor, Department of Oncology, University of Helsinki. Personal communication.

Safrai, Mary B. 2013. “Art Therapy in Hospice: A Catalyst for Insight and Healing.” *Art Therapy*, 30(3): 122–129. DOI: 10.1080/07421656.2013.819283

Salamonsen, Anita. 2013. “Doctor–patient communication and cancer patients’ choice of alternative therapies as supplement or alternative to conventional care.” *Scandinavian Journal of Caring Sciences*, 27: 70–76. doi:10.1111/j.1471-6712.2012.01002.x

Salhi, Bisan. 2016. “Beyond the Doctor’s White Coat: Science, Ritual, and Healing in American Biomedicine.” In: Peter J. Brown & Svea Closser. *Understanding and Applying Medical Anthropology*, 204–212. New York: Routledge.

Salmenperä, Liisa. 2002. “The use of complementary therapies among breast and prostate cancer patients in Finland.” *European Journal of Cancer Care*, 11: 44–50. doi:10.1111/j.1365-2354.2002.00295.x

Saramo, Samira, Eerika Koskinen-Koivisto & Hanna Snellman (eds). 2019. *Transnational Death*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Sartre, Jean-Paul. 1956. *Being and Nothingness*. New York: Philosophical Library.

Saunders, Benjamin, Jenny Kitzinger & Celia Kitzinger. 2015. “Anonymising interview data: Challenges and compromise in practice.” *Qualitative Research*, 15(5): 616–632. doi:10.1177/1468794114550439

Sax, William S. 2006. “Agency.” In: Jens Kreinath, Jan Snoek & Michael Stausberg (eds), *Theorizing Rituals, Volume 1: Issues, Topics, Approaches, Concepts*, 473–481. Leiden: Brill.

Schaefer, Donovan O. 2015. *Religious Affects: Animality, Evolution, and Power*. Durham & London: Duke University Press.

Schaepe, Karen Sue. 2011. "Bad news and first impressions: patient and family caregiver accounts of learning the cancer diagnosis." *Social science & medicine*. 73(6): 912–21. doi:10.1016/j.socscimed.2011.06.038

Schilbrack, Kevin. 2004. "Introduction: On the use of philosophy in the study of rituals." In: Kevin Schilbrack (ed.), *Thinking through Rituals*: *Philosophical Perspectives*, 1–30. New York: Routledge.

Schilbrack, Kevin. 2004. "Ritual metaphysics," In: Kevin Schilbrack (ed.), *Thinking through Rituals: Philosophical Perspectives*, 128–147. New York: Routledge.

Schilderink, Melissa & Eric Venbrux. 2019. "The postself in blogs about terminal illness." *Thanatos*, 8(2). https://thanatosjournal.files.wordpress.com/2020/01/schilderink_venbrux_postself-in-blogs.pdf (Accessed on 4/25/2020)

Schipke, Timothy. 2019. "The Chronic Sick Role: Its Time Has Come." *OMEGA - Journal of Death and Dying*. doi:10.1177/0030222819852848.

Schwan, Anne & Stephen Shapiro. 2011. *How to Read Foucault's Discipline and Punish*. London: Pluto Press. http://www.jstor.org/stable/j.ctt183p5zd (Accessed on 2/14/2017)

von Scheve, Christian. 2018. "A social relational account of affect." *European Journal of Social Theory*, 21(1): 39–59.

Seale, Clive. 1998. *Constructing Death: The Sociology of Dying and Bereavement*. New York & Cambridge, UK: Cambridge University Press.

Seebach, Sophie & Rane Willerslev. 2018. *Mirrors of Passing: Unlocking the Mysteries of Death, Materiality, and Time*. New York: Berghahn Books.

Sharon, Tamar. 2014. *Human Nature in an Age of Biotechnology: The Case for Mediated Posthumanism*. New York: Springer.

Shouse, Eric. 2005. "Feeling, Emotion, Affect." *M/C Journal*, 8(6). doi.org/10.5204/mcj.2443

Siltala, Markku. 2019. *Jälleenkohtaamisia: Vainajakokemukset sekä niiden koetut vaikutukset käsityksiin elämästä ja kuolemasta*. Doctoral dissertation. University of Helsinki, Faculty of Theology.

Siltala, Pirkko. 1985. "Kuolema ja psykoterapia." In: Jan-Erik Ruth & Pirkko Heiskanen (eds), *Kuolema elämän keskellä*. Helsinki: Otava.

Skinner, Jonathan. 2012. "A Four Part Introduction to the Interview: Introducing the Interview; Society, Sociology and the Interview; Anthropology and the Interview; Anthropology and the Interview – Edited". In Jonathan Skinner (ed.), *The Interview: An Ethnographic Approach*, 1–50. London: Bloomsbury Academic.

Smith, Jonathan A. & Virginia Eatough. 2019. "Looking Forward: Conceptual and Methodological Developments in Interpretative Phenomenological Analysis. Introduction to

the Special Issue." *Qualitative Research in Psychology*, 16(2): 163–165. doi:10.1080/14780887.2018.1540620

Smith, Jonathan A. & Mike Osborn. 2003. "Interpretative phenomenological analysis." In: Jonathan A. Smith (ed.), *Qualitative Psychology: A Practical Guide to Methods*, 51–80. London: Sage.

Smith, Jonathan A., Paul Flowers & Michael Larkin. 2009. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage Publications.

Smith, Lindsay & Arthur Kleinman. 2010. "Emotional engagements: Acknowledgement, advocacy, and direct action." In: James Davies & Dimitrina Spencer. *Emotions in the Field: The Psychology and Anthropology of Fieldwork Experience*. Stanford University Press.

Snoek, Jan. 2006. "Defining 'Rituals.'" In: Jens Kreinath, Jan Snoek & Michael Stausberg (eds), *Theorizing Rituals: Issues, Topics, Approaches, Concepts*, 3–15. Leiden: Brill.

Sofka, Carla. 2012. "Blogging: New Age Narratives of Dying, Death, and Grief." In: Illene Noppe Cupit, Kathleen Gilbert & Carla Sofka (eds), *Dying, Death, and Grief in an Online Universe: For Counselors and Educators*, 61–77. New York: Springer Publication.

Soja, Edward W. 1985. "The Spatiality of Social Life: Towards a Transformative Retheorisation." In: Gregory Derek & John Urry (eds), *Social Relations and Spatial Structures*, 91–127. Critical Human Geography. London: Palgrave.

Soja, Edward. 1989. *Postmodern Geographies: The Reassertion of Space in Critical Social Theory*. London: Verso Press.

Solomon, Robert C. 2005. "Subjectivity." In: *The Oxford Companion to Philosophy.* Oxford University Press. https://www-oxfordreference-com.libproxy.helsinki.fi/view/10.1093/acref/9780199264797.001.0001/acref-9780199264797-e-2440 (Accessed on 10/1/2020)

Sontag, Susan. 1978. *Illness as Metaphor*. New York: Farrar, Straus and Giroux.

Spinoza, Baruch (author) & George H. R. Parkinson (translator and editor). 2000. *Ethics*. Oxford University Press.

Stage, Carsten. 2014. "Online A-Liveness: A 'Rhythmanalysis' of Three Illness Blogs made by Rosie Kilburn, Jessica Joy Rees and Eva Markvoort," in Dorthe Refslund Christensen & Kjetil Sandvik (eds), *Mediating and Remediating Death*, 199–216. London: Routledge.

Stavrositu, Carmen. 2014. "Blogging" in Mary Beth Oliver & Arthur A. Raney (eds) *Media and Social Life*, 209–221. New York: Routledge.

Stewart, Miriam J., Edward Makwarimba, Linda I. Reutter, Gerry Veenstra, Dennis Raphael, and Rhonda Love. 2009. "Poverty, Sense of Belonging and Experiences of Social Isolation". *Journal of Poverty*, 13(2): 173–195.

Styrman, Tuula & Torniainen, Marika. 2018. *Kunnioittavan kosketuksen käsikirja: Ammatillinen hoitokohtaaminen sosiaali- ja terveysalalla*. Helsinki: PS-Kustannus.

Sudnow David. 1967. *Passing On: The Social Organization of Dying*. Englewood Cliffs, New Jersey: Prentice-Hall.

Suomen virallinen tilasto (SVT) 2015. “Väestörakenne. Vuosikatsaus 2015.” Helsinki: Tilastokeskus. http://www.stat.fi/til/vaerak/2015/01/vaerak_2015_01_2016-09-23_tie_001_fi.html (Accessed on 12/1/2020)

Surall, Vera, and Inga Steppacher. 2018. “How to Deal With Death: An Empirical Path Analysis of a Simplified Model of Death Anxiety.” *OMEGA - Journal of Death and Dying*, October 2018. doi:10.1177/0030222818808145.

Swan, Astrid. 2017. “Body talk–Breast cancer aftermath.” *One Quart Magazine*. https://onequartmagazine.com/life/07/2016/breast-cancer/ (Accessed on 5/19/2019)

Taira, Teemu. 2012. “More visible but limited in its popularity: atheism (and atheists) in Finland.” *Approaching Religion*, 2(1): 21–35. doi.org/10.30664/ar.67489

Taira, Teemu P. 2015. “Finland: recent trends and patterns in religion, secularism and atheism.” *Analyses: Observatoire des religions et de la Laïcite*. http://www.o-re-la.org/index.php?option=com_k2&view=item&id=1424%3Afinland-recent-trends-and-patterns-in-religion-secularism-and-atheism&Itemid=85&lang=fr (Accessed on 12/1/2020)

Tambiah, Stanley J. 1968. “The Magical Power of Words.” *Man: The Journal of the Royal Anthropological Institute*, 3(2): 175–208.

Tambiah, Stanley J. 1979. *A Performative Approach to Ritual*. Oxford University Press.

Tambiah, Stanley J. 1990. *Magic, Science and Religion and the Scope of Rationality*. New York: Cambridge University Press.

Tarkkanen, Maija; Kristiina Tyynelä-Korhonen & Sirkku Jyrkkiö. 2020. ”Parantumattoman syövän lääkehoito elämän loppuvaiheessa - hyötyä vai haittaa?” *Lääketieteellinen Aikakauskirja Duodecim*, 136(7): 768–774.

Taylor, Charles. 1994. “The Politics of Recognition.” In: Amy Gutmann (ed.), *Multiculturalism: Examining the Politics of Recognition*, 25–73. Princeton, NJ: Princeton University Press.

TENK (Finnish National Board on Research Integrity). 2009. “Ethical principles of research in the humanities and social and behavioural sciences and proposals for ethical review.” https://www.tenk.fi/sites/tenk.fi/files/ethicalprinciples.pdf (Accessed on 12/1/2020)

Tercier, John Anthony. 2005. *The Contemporary Deathbed: The Ultimate Rush.* New York: Springer.

Thrift, Nagel. 2008. *The Non-Representational Theory: Space, Politics, Affect*. New York: Routledge.

Throop, C. Jason. 2003. “Articulating Experience.” *Anthropological Theory* 3(2): 219–241. doi:10.1177/1463499603003002006.

Tiedebarometri 2019. Tutkimus suomalaisten suhtautumisesta tieteeseen ja tieteellis-tekniseen kehitykseen. Report by Pentti Kiljunen. http://www.tieteentiedotus.fi/files/Tiedebarometri_2019.pdf (Accessed on 12/1/2020)

Tilastokeskus. 2014. *Väestö* (data file). http://www.stat.fi/tup/suoluk/suoluk_vaesto.html#vaestorakenne (Accessed on 8/1/2016)

Timmermans, Stefan & Marc Berg. 2003. “The practice of medical technology.” *Sociology of Health & Illness*, 25: 97–114. doi:10.1111/1467-9566.00342

Toivoniemi, Mikko. 2015. “Spinoza ja elämä osa 5: affektien kivijalat – halu, ilo ja suru.” https://schizoblog.me/2015/02/26/spinoza-ja-elama-osa-5-affektien-kivijalat-halu-ilo-ja-suru/ (Accessed on 3/12/2018)

Topo, Päivi & Sonja Iltanen-Tähkävuori. 2010. “Scripting patienthood with patient clothing.” *Social Science & Medicine,* 70(11): 1682–1689.

Truant, Tracy L., Antony J. Porcino, Brenda C. Ross, Margurite E. Wong & Carla T. Hilario. 2013. “Complementary and Alternative Medicine (CAM) Use in Advanced Cancer: A Systematic Review.” *The Journal of Supportive Oncology*, 11(3): 105–113.

Tuan, Yi-Fu. [1977] 2001. *Space and Place: The Perspective of Experience.* Minneapolis: University of Minnesota Press.

Tuohimaa, Sinikka. 2004. *Parantavat sanat*. Helsinki: Kirjapaja.

Turner, Bryan S. 1995. *Medical Power and Social Knowledge* (2nd Edition). London: Sage Publications.

Turner, Victor. 1961. *The Ritual Process: Structure and Anti-Structure*. Harmondsworth, UK: Penguin Books.

Turner, Victor. 1970. *The Forest of Symbols: Aspects of Ndembu Ritual*. Ithaca, NY & London: Cornell University Press.

Tyrväinen, Liisa, Mikko Kurttila, Tuija Sievänen & Seija Tuulentie (eds) 2014. *Hyvinvointia metsästä*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Tyrväinen, Liisa, Ann Ojala, Marjo Neuvonen, Katja Borodulin & Timo Lanki. 2019. ”Effets bénéfiques de la forêt sur la santé et le bien-être. L’expérience de la recherche finlandaise.” *Santé Publique*, 1(HS): 249–256. https://www.cairn.info/revue-sante-publique-2019-HS-page-249.html (Accessed on 12/12/2019)

Utriainen, Terhi. 1999. *Läsnä, riisuttu, puhdas: uskontoantropologinen tutkimus naisista kuolevan vierellä*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Utriainen, Terhi. 2000. “Situated Bodies and Others Making Religion: Phenomenology of the Body and the Study of Religion.” *Temenos – Nordic Journal of Comparative Religion*, 36. https://doi.org/10.33356/temenos.4869

Utriainen, Terhi. 2010. “Agents of De-differentiation: Women Care-Givers for the Dying in Finland.” *Journal of Contemporary Religion*, 25(3): 437–451.

Utriainen, Terhi. 2016. “Ritually Framing Enchantment: Momentary religion and everyday realities.” *Suomen Antropologi: Journal of the Finnish Anthropological Society*, 41(4): 46–61. https://journal.fi/suomenantropologi/article/view/63058 (Accessed on 12/1/2020)

Utriainen, Terhi. 2020. “Lived Religion Meets Secular Life: Dynamics of Framing and the Subjunctive Power of Ritual.” *Journal of Contemporary Religion.* DOI: 10.1080/13537903.2020.1759900

Vainio, Seppo. 2014. “Kuoleman ja kuolemattomuuden biologia.” In: Outi Hakola, Sari Kivistö & Virpi Mäkinen (eds), *Kuoleman kulttuurit Suomessa*, 181–201. Helsinki: Gaudeamus.

Vaittinen, Tiina. 2015. “The power of the vulnerable body: A new political understanding of care.” *International Feminist Journal of Politics*, 17(1): 100–118. doi:10.1080/14616742.2013.876301

Van Dongen, Els & Sylvie Fainzang. 1998. “Editorial: Medical anthropology at home: Creating distance.” *Anthropology & Medicine*, 5(3): 245–250.

van der Geest, Sjaak. 2005. “‘Sacraments’ in the Hospital: Exploring the Magic and Religion of Recovery.” *Anthropology & Medicine*, 12(2): 135–150. doi:10.1080/13648470500139957

van Hout, Annemarie, Jeannette Pols & Dick Willems. 2015. “Shining trinkets and unkempt gardens: on the materiality of care.” *Sociology of Health & Illness*, 37(8): 1206–1217.

Vellenga, Sipco, J. 2008. “Longing for Health. A Practice of Religious Healing and Biomedicine Compared.” *Journal of Religion and Health,* 47: 326–337. https://doi.org/10.1007/s10943-008-9175-0

Venhorst, Claudia. 2012. *Muslims Ritualising Death in the Netherlands*. Zürich: Lit Verlag.

Verdeber, Stephen F. & Ben J. Refuerzo. 2006. *Innovations in Hospice Architecture*. New York: Taylor & Francis.

Vessey, David. 2009. “Gadamer and the Fusion of Horizons,” *International Journal of Philosophical Studies*, 17(4): 531–542. doi:10.1080/09672550903164459

Virtaniemi, Matti-Pekka. 2017. *Elämän päätösjakson haaste: ALS-tautiin sairastuneen eksistentiaalinen prosessi ja uskonnollinen spiritualiteetti.* Helsingin yliopisto.

Visser, Renske C. 2017. “’Doing death’: Reflecting on the researcher’s subjectivity and emotions”. *Death studies*. 41(1): 6–13.

Vuolanto, Pia, Laura Kemppainen, Teemu Kemppainen & Johanna Nurmi. 2020. “Täydentävien ja vaihtoehtoisten (CAM) hoitojen käyttö Suomessa.” *Sosiaalilääketieteellinen Aikakauslehti*, 57(1). doi.org/10.23990/sa.80288

Vuolanto, Pia, Minna Sorsa, Pauliina Aarva & Kaija Helin. 2018. “Katsaus suomalaiseen CAM-tutkimukseen.” *Sosiaalilääketieteellinen Aikakauslehti,* 55(3): 243–259.

Vähäkangas, Auli. M. & Suvi-Maria K. Saarelainen. 2019. “Relationality as the basis of hope: embodied experiences during life-threatening illness.” In: Auli Vähäkangas, Sivert Angel & Kristine Helboe Johansen (eds), *Reforming practical theology: The politics of body and* space, 76–82. Tübingen: International Academy of Practical Theology.

Walsh, Brian. 2012a. “A Post-Structuralist View of Evidence-Based Medicine (EBM).” In: Nikolaos Sitaras (ed.), *Evidence Based Medicine: Closer to Patients or Scientists?*, 55–78. doi:10.5772/37145

Walsh, Brian. 2012b. *A Post-structuralist Viewpoint on Evidence-based Medicine*. PhD dissertation. University of Otago, New Zealand.

https://ourarchive.otago.ac.nz/bitstream/handle/10523/2181/WalshBrian2012PhD.pdf?sequence=3&isAllowed=y (Accessed on 2/2/2018)

Walsh, Mike & Pauline Ford. 1989. "Rituals in nursing—a day in the ward." *Nursing Times*, 85(43): 45–48.

Walter, Tony. [1994] 2002. *The Revival of Death.* London: Routledge.

Walter, Tony. 1996a "Ritualising Death in a Consumer Society." *Journal of the Royal Society of Arts*, 144(5468): 32–40. www.jstor.org/stable/41377047 (Accessed on 12/1/2020)

Walter, Tony. 1996b. *The Eclipse of Eternity. A Sociology of the Afterlife*. London: Macmillan Press.

Warf, Barney & Santa Arias (eds). 2008. *The Spatial Turn: Interdisciplinary Perspectives*. New York: Routledge.

Waronen, Matti. 1898. *Vainajainpalvelus muinaisilla suomalaisilla*. Helsinki: Suomalaisen Kirjallisuuden Seura.

Weeks, Jane C., Paul J. Catalano, Angel Cronin et al. 2012. "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer." *The New England Journal of Medicine*, 367: 1616–1625. doi:10.1056/NEJMoa1204410

Welch, John S. 2003. "Ritual in Western Medicine and Its Role in Placebo Healing." *Journal of Religion and Health*, 42(1): 21–33. doi.org/10.1023/A:1022260610761

WHO (World Health Organization). 2019. "Definition of palliative care." https://www.who.int/cancer/palliative/definition/en/

WCPA (World Palliative Care Alliance) & WHO (World Health Organization). 2014. *Global atlas of palliative care at the end of life*. https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf?ua=1.9 (Accessed on 11/21/2019)

Wicker, Paul. 1999. "Rituals." *British Journal of Theatre Nursing*, 9(8): 327.

Williams Oliver S. & Ellen Annandale. 2014. "Embodied Subjectivity". In: Michalos A.C. (eds) *Encyclopedia of Quality of Life and Well-Being Research*. Dordrecht: Springer.

Williams, Ron G. & James W. Boyd. 1993. *Ritual Art and Knowledge: Aesthetic Theory and Zoroastrian Ritual*. University of South Carolina Press.

Williams, Ron G. & James W. Boyd. 2006. "Aesthetics." In: Jens Kreinath, Jan Snoek & Michael Stausberg (eds), *Theorizing Rituals: Issues, Topics, Approaches, Concepts*, 285–305. Leiden: Brill. https://doi.org/10.1163/9789047410775

Wilson, Edward O. 1984. *Biophilia*. Cambridge: Harvard University Press.

Wolf, Z.R. 2014. *Exploring Rituals in Nursing: Joining Art and Science*. New York: Springer Publishing Company.

Woodhead, Kate, E. W. Taylor, G. Bannister, T. Chesworth, P. Hoffman & H. Humphreys. 2002. "Behaviours and rituals in the operating theatre." *Journal of Hospital Infection*, 51(4): 241–255. doi.org/10.1053/jhin.2002.1220

Woodhead, Linda. 2011. “Five concepts of religion.” *International Review of Sociology*, 21(1): 121–143. DOI: 10.1080/03906701.2011.544192

Woodthorpe, Kate. 2011. “Researching death: Methodological reflections on the management of critical distance.” *International Journal of Social Research Methodology*, 14(2): 99–109. doi:10.1080/13645579.2010.496576

Woolf, Virginia. 1985. *Moments of Being*. San Diego, CA: Harvest/Harcourt, Inc.

Worpole, Ken. 2010. “Making Hospice Space.” In: Jenny Hockey, Carol Komaromy & Kate Woodthorpe (eds). *The Matter of Death: Space, Place and Materiality*, 35–51. Basingstoke, UK: Palgrave Macmillan.

Wright, David. 2012. *Delirium and the good death: An ethnography of hospice care*. PhD dissertation. University of Ottawa, School of Nursing. https://pdfs.semanticscholar.org/8d2c/493a721f0bd2a87e5dfd83ce41f541fa3c3f.pdf (Accessed on 12/1/2020)

Yanikkerem, Emre, Meral Özdemir, Hilal Bingol, Ayse Tatar, Gülten Karadeniz. “Women's attitudes and expectations regarding gynaecological examination.” 2009. *Midwifery*, 25(5): 500–508. doi:10.1016/j.midw.2007.08.006

Yeganeh, Hamid. 2019. “An analysis of emerging trends and transformations in global healthcare.” *International Journal of Health Governance*, 24(2): 169–180. doi.org/10.1108/IJHG-02-2019-0012

APPENDICES

Appendix 1: Research Information

Tutkimustiedote

Tutkimus toiveista ja tarpeista palliatiivisessa hoidossa

Kysyn tässä tiedotteessa halukkuuttanne osallistua tutkimukseen.

Teen Helsingin yliopiston humanistiseen tiedekuntaan väitöstutkimusta (tutkimusnumero), jossa selvitetään palliatiivisessa hoidossa olevien potilaiden kokemuksia, toiveita ja tarpeita. Tutkimusta ohjaavat professori René Gothóni ja dosentti Terhi Utriainen uskontotieteen oppiaineesta. HUS:issa tutkimuksesta vastaa lääkäri Tiina Saarto.

Kerään aineistoa tutkimustani varten havainnoimalla arkisia, jokapäiväisiä tapahtumia hoitoyksiköissä, osallistumalla vapaamuotoisiin keskusteluihin potilaiden, omaisten ja henkilökunnan kanssa sekä haastattelemalla (kerran tai useammin) tutkimuksesta kiinnostuneita potilaita. Haastattelut äänitetään potilaan suostumuksella. Saatte itse valita ne hetket, jolloin tutkija saa olla läsnä potilashuoneessanne.

Myös yleiset tiedot sairaudestanne ja hoitolinjastanne ovat osa tutkimusaineistoa. Tiedot auttavat tutkijaa ymmärtämään kokemuksianne. Nämä tiedot kysytään pääasiassa Teiltä itseltänne. Osa tiedoista, kuten tarkemmat tiedot sairaudestanne kerätään sairauskertomuksesta.

Osallistuminen tutkimukseen tarkoittaa käytännössä sitä, että tutkija saa tutkimuksessaan käyttää Teitä koskevaa aineistoa, jota kerätään yllä kuvatulla tavalla, kuitenkin niin, että Teitä ei voida siitä tunnistaa.

Vapaaehtoisuus

Tutkimukseen osallistuminen on vapaaehtoista ja siihen pyydetään Teiltä kirjallinen suostumus. Osallistumisesta kieltäytyminen ei vaikuta millään tavoin saamaanne hoitoon tai kohteluun. Voitte myös halutessanne keskeyttää osallisuutenne tutkimuksessa. Tutkimus ei häiritse hoitotoimenpiteitänne, eikä siitä aiheudu Teille ylimääräisiä sairaalakäyntejä tai kustannuksia.

Luottamuksellisuus

Kaikki tutkijan kanssa käydyt keskustelut ja tutkijalle annetut henkilö- ja potilastiedot ovat täysin luottamuksellisia. Tutkimusaineistoa käsitellään ja säilytetään tutkimuksen ajan luottamuksellisesti ja tutkittavien henkilöllisyyttä suojaten. Henkilötietojanne ei luovuteta tutkimushankkeen ulkopuolisille henkilöille. Henkilöllisyytenne ei ole tunnistettavissa valmiissa tutkimusjulkaisuissa.

Toivon, että tämän tutkimuksen avulla palliatiivista hoitoa voidaan kehittää entistä kokonaisvaltaisemmaksi hoitomuodoksi. Vastaan mielelläni kaikkiin tutkimukseen liittyviin kysymyksiin.

Osallistumisenne vahvistamiseksi pyydän Teitä ystävällisesti allekirjoittamaan oheisen suostumuslomakkeen.

Kiittäen,
Maija Butters FM, Helsingin yliopisto, Maailman kulttuurien laitos
Puhelin: XXX-XXXXXXX Sähköposti: maija.xxxxxx@helsinki.fi

Tutkimuksen ohjaaja professori René Gothóni
Uskontotiede, Maailman kulttuurien laitos
Puh. XX-XXX XXXX

Tutkimuksen vastaava lääkäri Tiina Saarto
vs. syöpäklinikkaryhmän johtaja
HYKS, Syöpätautien klinikka, puh. XXX-XXXXXX

Appendix 2: Research Consent Form

Potilaan tutkimussuostumus

Minua _____ on pyydetty osallistumaan FM Maija Buttersin suorittamaan väitöskirjatutkimukseen palliatiivisten potilaiden toiveista, tarpeista ja kokemuksista.

Olen saanut, lukenut ja ymmärtänyt tutkimuksesta kertovan tiedotteen (versio 11/2013). Olen myös saanut tutkijalta riittävän selvityksen tutkimuksesta ja sen yhteydessä suoritettavasta tietojen keräämisestä, käsittelystä ja luovuttamisesta.

Suostun osallistumaan tutkimukseen ja annan luvan itseäni koskevien, tutkimuksen kannalta tarpeellisten tietojen keräämiseen. Minusta tutkimuksen aikana kerättyjä tietoja käsitellään luottamuksellisesti. Henkilöllisyyttäni ei voida päätellä valmiista tutkimusjulkaisuista.

Osallistumiseni tähän tutkimukseen on täysin vapaaehtoista. Olen tietoinen siitä, että voin peruuttaa tämän suostumuksen ja luopua tutkimuksesta, jolloin minusta kerättyjä tietoja ei käytetä enää tutkimustarkoituksessa. Tutkimuksesta kieltäytyminen tai suostumukseni peruttaminen ei vaikuta hoitooni tai kohteluuni millään tavalla.

Haastatteluni saa _____
ei saa _____

äänittää myöhempää analyysiä varten.

Tutkija saa _____
ei saa _____

ottaa yhteyttä omaiseeni _____ (omaisen nimi).

Allekirjoituksellani vahvistan osallistumiseni tähän tutkimukseen.

_____ _____
potilaan allekirjoitus päiväys

_____
Tutkija FM Maija Butters

Appendix 3: Research Participants

1. **AILI**
   A woman in her seventies whom I met in the day hospice group. She was actively involved with the research for a number of years. Aili is still alive and well today.

2. AURORA
   An older woman in her eighties whom I met on the hospice ward. We met quite often, but I never conducted an actual interview with her for health reasons other than her terminal illness. Aurora did not die on the ward. After her condition ameliorated, she was moved into an elderly home, where she lived for another year before she passed away. I continued seeing her until her death.

3. **EEVA**
   A woman in her seventies whom I met on the hospice ward. We met often and had many one-on-one conversations. She died on the hospice ward only a few months after I met her.

4. **HEIDI**
   A woman in her fifties whom I met on the hospice ward. We had a few intense conversations but she died on the hospice ward only some weeks after I met her.

5. HEIKKI
   A man in his sixties who was the author of the blog "Sairaan rakas elämä." I had already been following Heikki's blog when I finally met him via other patients. We met a few times and I interviewed him about his blog. Heikki survived his cancer.

6. **HELENA**
   A woman in her forties whom I already knew before the research. She mostly received home care and was admitted to a healthcare center to receive palliative care at the end of her life. I met her a couple of times and interviewed her for the study.

7. **INKERI**
   A woman in her sixties whom I met at the day hospice. I knew Inkeri for about half a year, but we met often and talked a lot one-on-one. She died on the hospice ward.

8. IRMA
   An older woman in her nineties whom I met at the day hospice and who was admitted to the hospice ward soon thereafter. We talked, yet there was no time for an interview before her condition deteriorated. She died a couple months later.

9. **KIMMO**
   A man in his fifties whom I met on the hospice ward. He spent some time on the ward and then moved to home care. I met him few times at the hospice and later also at his home, and we had many one-on-one conversations. He died in the ER after a sudden collapse.

10. KIRSI
    A woman in her sixties whom I met at the day hospice. We met only a couple of times and had one long interview. She died several months later on the hospice ward.

11. KRISTIINA
    A woman in her sixties whom I was invited to interview via our common friends. I met with Kristiina few times at her care place.

12. **MARJO RIITTA**
    A woman in her forties who maintained a blog called "Syöpä tarinoituu todeksi." I followed Marjo-Riitta's posts and finally contacted her for further interviews. She died in a medical care facility three months after our interviews.

13. **MARTTI**
    A man in his sixties whom I met on the oncology ward. I kept meeting Martti over the years at various care locations and at home. We had many conversations and interviews. Today he is at home and doing well.

14. MATTI
    A man in his sixties whom I was invited to interview by him and his close relative. We met only once and spoke on the phone one time, but nonetheless had an intense conversation.

15. **OIVA**
    A man in his seventies whom I met in the day hospice group. We met regularly for months and had a number of conversations. I followed Oiva to the end and met with him still on the hospice ward during his last weeks and days.

16. PETER
    A man in his fifties whom I met on the hospice ward. We met a few times, and I had one longer interview with him. He died after a few weeks on the hospice ward.

17. **PEKKA**
    A man in his fifties whom I met on the oncology ward. We met a few times and had some long conversations. After Pekka was sent home I visited him there. He died at home a couple of months later, and afterwards I talked with his wife about Pekka's end of life.

18. RAUHA
    A woman in her seventies whom I met in the day hospice. We met and talked a few times but I never had a personal interview with her before her death on the hospice ward.

19. **SIRU**
    A woman in her fifties whom I met in the day hospice. I knew Siru for years and we met regularly and talked often. She died on the hospice ward.

20. TAINA
    A woman in her sixties whom I met in the day hospice. I met her often for a period of time, but we conducted only one interview together.

21. **VIVIAN**
    A woman in her fifties whom I got to know in the day hospice. I knew Vivian for several months, and we met a few times for interviews at the day hospice, at her home, and on the hospice ward, where she died.

Appendix 4: List of Possible Interview Questions

Questions around the illness

- How and when did you learn about your illness?
- What was your initial reaction?
- Has your attitude toward the illness changed in the course of time? If yes, how? (Further questions around this, depending on the answers)
- What is the most important thing in life to you at this moment?
- Could you say what was most important before the illness? (Further questions around this, depending on the answers)

Questions around daily life at the moment

- Tell me something about your typical day?
- What is the best part of the day or best thing in your day? What is the dullest?
- Have you noticed any (new) routines that have become important to you since your illness?

Relationships

- Have your relationships to your closed ones changed?
- Are there people, old friends, for instance, you would like to contact? Have you done that?
- (How) has your relationship changed since becoming ill?
- How about the relationship with time? With space/place?

Emotions, expectations

- Do you have any specific wishes or dreams for today / for the future?
- Do you have fears? Of what?
- Worries? Etc. (Further questions around this, depending on the answers)

Worldview

- Do you belong to the Church (Lutheran or other)?
- Do you (ever) think existential thoughts? ("God," "supernatural," "afterlife"?) (Questions modified, according to the person)
- Have you talked about these things with anybody?
- Would you like to talk about them with somebody?
- Do you have any experiences in regard to supernatural phenomena?
- What is your understanding about the meaning of life?
- Has this changed over the years?

If the person is able to talk about death

- Have you lost someone close to you?
- What kinds of thoughts/feelings did this cause in you?
- Do you have any specific wishes in relation to your own death?
- Would you like to say goodbyes? In some specific way? How/in what kind of circumstances/to whom? Have you done this?
- Would you like to leave a letter or a recording for someone? Have you done so?
- Do you have any experiences in relation to the afterlife?
- Is there anything else that you would like to talk about?